



Royal Commission
into Violence, Abuse, Neglect and Exploitation
of People with Disability

Enabling autonomy and access



Final Report
Volume 6

September 2023

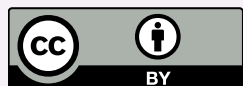
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Acknowledgement of Country

The Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (the Royal Commission) acknowledges Australia's First Nations peoples as the Traditional Custodians of the lands, seas and waters of Australia, and pays respect to all First Nations Elders past, present and emerging.

We recognise their care for people and country. In particular, we acknowledge the Traditional Custodians of the lands on which our offices are based: the Gadigal people of the Eora Nation where our Sydney office stands, the Jagera and Turrbal people as Traditional Owners and Custodians of the lands on which the city of Brisbane is located and the Ngunnawal and Ngambri peoples upon whose land the city of Canberra is located.

We pay our respects to all First Nations people with disability and recognise the distinct contributions they make to Australian life and to the outcome of this inquiry.

Acknowledgement of people with disability

The Royal Commission acknowledges people with disability who fought and campaigned long and hard for the establishment of this Royal Commission.

We acknowledge the courage and generosity of people with lived experience of disability who shared their knowledge and experiences of violence, abuse, neglect and exploitation with the Royal Commission. Their contributions to the Royal Commission have been indispensable in framing recommendations designed to achieve a more inclusive society that supports the independence of people with disability and their right to live free from violence, abuse, neglect and exploitation.

Content warnings

This report contains information about violence, abuse, neglect and exploitation that may be distressing to readers.

The report contains first-hand accounts of violence, abuse, neglect and exploitation. As a result, some direct quotes in the report may contain language that may be offensive to some people.

First Nations readers should be aware that some information in this report may have been provided by or refer to First Nations people who have passed away.

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Key terms

accessible

Environments, facilities, services, products and information that people are able to use and interact with in a way that suits their needs.

administrator or financial manager

A person or officer appointed, often by a tribunal, to make decisions about the financial affairs of another person.

advocacy

Disability advocacy refers to acting, speaking or writing to promote, protect and defend the rights and interests of people with disability, including human rights.

audio description

Audio description is an accessibility measure that is an audio narration of what is appearing visually on a stage or screen for people who are blind or have low vision. During gaps in dialogue, the narration describes visual elements such as scenes, settings, actions and costumes.

augmented and alternative communication

Methods of communication personalised to enable the participation of a person who may experience barriers to spoken communication. They include unaided forms, such as eye contact, gestures, facial expression, vocalisations and sign language, and aided forms that use devices to communicate.

Auslan

Auslan is the name for Australian Sign Language and is the main language of Australia's Deaf community.

Australian Disability Enterprises (ADEs)

Generally a not-for-profit organisation that provides employment for people with moderate to severe disability who need significant support to work.

autonomy

A person's right and freedom to make decisions, control their life and exercise choice.

braille

A tactile alphabet for people who are blind, d/Deafblind or who have low vision. It uses raised dots that are interpreted through touch.

captioning

The act of converting audio content into a text version. This can be used in a range of environments, such as for television/streaming broadcast, live event or webcast. While subtitles only contain dialogue, captions include music, sound effects, background sounds and non-verbal content, such as whether a speaker has an accent.

co-design

A design process where stakeholders are equal partners and take leadership roles in the design of products, services, systems, policies, laws and research.

co-production

An extension of 'co-design', where stakeholders are involved in the decision-making, implementation and evaluation of products, services, systems, policies, laws and research.

cultural safety

An outcome that respects, supports and empowers the cultural rights, identity, values, beliefs and expectations of First Nations peoples while providing quality services that meet their needs.

culturally and linguistically diverse

This broad term describes communities with diverse languages, ethnic backgrounds, nationalities, traditions, societal structures and religions. This includes people with a different heritage or linguistic background than dominant Australian culture and language, people with dual heritage, and people who are migrants and refugees. Some members of the Deaf community and other Auslan users also identify as members of a cultural minority.

Deaf

‘Deaf’ (with a capital ‘D’) is used to describe people who use sign language such as Auslan to communicate, and who identify culturally as members of the signing Deaf community.

deaf

The word ‘deaf’ (with a lower case ‘d’) is a broader term than Deaf (with a capital ‘D’). It is used to describe the physical condition of not hearing, and also to describe people who are physically deaf but do not identify as members of the signing Deaf community. See also ‘hard of hearing / hearing impaired’.

d/Deafblind

The term ‘d/Deafblind’ refers to people who have some hearing and vision, as well as people who are totally deaf and blind. The most common forms of communication used by people who are d/Deafblind in Australia are:

- speech, oral and aural communication
- sign language including a variety of ways of receiving sign language such as close range, visual frame and tactile, hand over hand signing
- d/Deafblind fingerspelling.

decision-making ability

The ability of a person to make a particular decision with the provision of relevant and appropriate support at a time when a decision needs to be made.

dignity of risk

Affording a person the right and dignity to take risks.

disability representative organisation (DRO)

A peak organisation providing systemic advocacy and representation for people with disability.

Easy Read

Easy Read format is a way of presenting written information to make it easier to understand. It typically uses simple words, short sentences, accessible fonts and layouts, and images or photos to assist in illustrating the information.

enduring representation agreement

An arrangement under which a person appoints an enduring representative to make decisions for them when they do not have decision-making ability for those decisions.

enduring representative

A person appointed by another person under an enduring representation agreement to make decisions for them.

First Nations peoples

The Aboriginal people of mainland Australia, Tasmania and other islands off the continent, and the people of the Torres Strait Islands. This term reflects the social and governance structures and systems in place prior to colonisation.

Where people we engaged with identified themselves as either 'Aboriginal' or 'Torres Strait Islander' or referred to themselves by reference to their language group, we have respected their personal choices.

group home

A house that accommodates a number of people with disability as their residential home. The term 'group home' may also refer collectively to both the physical accommodation and provision of specialist disability supports to residents in the home.

guardian

Someone who is appointed under a guardianship order to make decisions about another person's health care, finances, accommodation, services, relationships or some other personal matters.

guardianship or administration law

Laws, found in both statute and at common law, that provide for the appointment, by a tribunal or court, of a substitute decision-maker. The circumstances of this appointment are generally where it has been determined a person does not have the capacity to make the particular decision that needs to be made, and there is a need to appoint a substitute decision-maker to make that decision on the person's behalf.

guardianship or administration orders

Legal decisions made by courts or tribunals that can allow a person to make decisions on another person's behalf.

informal supports

The social support networks that provide protection for people with disability by increasing connections, relationships and visibility in the wider community

involuntary sterilisation

Involuntary sterilisation is an irreversible surgical procedure that permanently prevents reproduction, performed on a person without their full, free and informed consent. This is sometimes referred to as forced sterilisation. Coerced sterilisation involves situations where a person is pressured, induced or deceived to gain their consent for sterilisation, and they may not understand the full implications of sterilisation.

legal capacity

A person's decisions and actions being recognised and respected by the law. It refers to both legal standing (the ability to hold rights and duties, and to be recognised as a legal person) and legal agency (the ability to exercise these rights and duties and to perform acts with legal effects).

LGBTIQA+

An internationally recognised acronym used to describe lesbian, gay, bisexual, trans and gender diverse, intersex, queer, questioning and asexual people and communities.

low vision/vision impaired/blind

People who have low vision, or who are blind or vision impaired, have reduced vision or are unable to see.

menstrual suppression

The use of medication to suppress menstruation for reasons other than for contraception or to treat a medical condition. Menstrual suppression is considered a chemical restraint.

representation order

A statutory order under which a tribunal appoints a representative to make certain decisions for another person who does not have decision-making ability for those decisions, as a measure of last resort.

representative

A person appointed under a representation order to make decisions on behalf of another person.

represented person

A person who has a representative or enduring representative appointed to make a decision when they do not have decision-making ability for that decision.

restrictive practice

Any action, approach or intervention that has the effect of limiting the rights or freedom of movement of a person. Restrictive practices include physical restraints, chemical restraints, mechanical restraints, environmental restraints and seclusion.

substitute decision-making

A range of processes and regimes that involve a person making decisions on another person's behalf. Substitute decision-making includes appointment of guardians, administrators and financial managers to make certain decisions on another person's behalf.

support agreement

An arrangement under which a person formally appoints a supporter to assist them in making decisions.

support order

A statutory order made by a tribunal, appointing a supporter to assist a person to make their own decisions.

supported decision-making

Processes and approaches that assist people to make a decision, including by giving them the tools they need to make the decision for themselves. Supported decision-making does not mean making a decision for or on behalf of another person.

supported person

A person who is supported in making decisions by a supporter appointed under a support order or support agreement.

supporter

Someone who provides support to a person with disability. This may be support for decision-making. A supporter may be appointed under a support order or support agreement to support a person with disability in making decisions.

will and preferences

‘Will’ means larger life goals, political perspectives, emotional and spiritual development and views, gender and sexual identity. ‘Preferences’ means choices regarding day to day activities, aesthetic preferences, and similar.¹

Summary

Our terms of reference recognise the human rights of people with disability, including ‘respect for their inherent dignity and individual autonomy’.² This echoes the first general principle of the *Convention on the Rights of Persons with Disabilities (CRPD)*.³ Dignity and autonomy are essential to a more inclusive society that supports the independence of people with disability and their right to live free from violence, abuse, neglect and exploitation. Dignity and autonomy depend on access to the services and supports a person requires to meet their fundamental needs. Choice, independence and dignity of risk are part of the foundation of our vision for an inclusive Australia.

Autonomy is a person’s right and freedom to make decisions, control their life and exercise choice. People with disability can only access environments, facilities, services, products and information if they are able to use and interact with them in a way that responds to their needs.

These two concepts of autonomy and access are closely interrelated. This volume examines what governments, public authorities, organisations and the community can do to better enable the autonomy of and access for people with disability.

I am an independent thinker, and am the decision maker in my life. I know how I would like things to happen in my life, the only reason this doesn’t always happen is because people don’t spend the time to find out how best to communicate with me ...⁴

At Public hearing 31, ‘Vision for an inclusive Australia’, Mr Gerard Quinn, the United Nations Special Rapporteur on the rights of persons with disabilities, described how the *CRPD* focuses on ‘the common humanity’ between people with disability and others.⁵ He said this requires, ‘restoring to people with disabilities power over their own lives, autonomous decision-making over their own lives, in as much as any of us have that capacity’.⁶ This requires an accessible society that enables people with disability to make those decisions as they see fit in the context of their own lives, needs and aspirations.

An inclusive society that enables the autonomy of people with disability also recognises the role of relationships and interdependence.⁷ We are all embedded in relationships, and these influence our ability to make decisions about our lives.⁸ As for everybody, the extent to which people with disability are able to live the life they want, and be seen, heard and respected, largely depends on the people, systems and structures around them.

Despite the ‘myth of independence’, many people, if not all of us, require support to exercise our autonomy.⁹ The former United Nations Special Rapporteur on the rights of persons with disabilities, Ms Catalina Devandas Aguilar, noted:

everyone needs support from others at some stage, if not throughout their life, to participate in society and live with dignity. Being a recipient of support and offering support to others are roles we all share as part of our human experience, regardless of impairment, age or social status.¹⁰

Over the course of the Royal Commission, we heard there are numerous barriers to people with disability being able to exercise autonomy. These include:

- being unable to access essential information or to communicate effectively because of an absence of reasonable adjustments
- a lack of support for decision-making
- not having access to an independent advocate
- systemic neglect and discrimination in the healthcare system
- the overuse of restrictive practices against people with disability.

These barriers can constitute systemic neglect and exacerbate the violence, abuse, neglect and exploitation experienced by people with disability. This volume recommends solutions to overcome these barriers and highlights the need for structural reforms to enable autonomy and access.

Accessible information and communications are vital for people with disability to live the lives they want and access the services they need. **Chapter 1** focuses on information and communications. It looks at how information is often inaccessible for people with disability, and the impact this has – particularly in emergency situations – where the consequences can be life or death. This chapter also explores the role of interpreters in supporting people with disability to understand and participate in decisions that affect them.

Chapter 2 is about decision-making. It examines the extent to which people with disability have decisions made on their behalf, and the range of negative consequences that can result. It examines how supported decision-making is key to enabling the autonomy of people with disability. It recommends reform of guardianship and administration laws to embed supported decision-making. It also makes recommendations directed at changing attitudes, policies and practice to better recognise and enable supported decision-making.

Chapter 3 addresses advocacy and informal supports. Access to advocacy and informal support networks are vital to realise autonomy and prevent violence, abuse, neglect and exploitation. This chapter looks at issues preventing people with disability from accessing safe and timely advocacy, and the changes needed to ensure disability advocacy providers meet demand for culturally safe services.

Chapter 4 focuses on the health care system. Access to safe and high-quality health care is critical for people with disability to live the kind of life they choose. This chapter looks at why people with disability receive poor care, the wrong care, or sometimes no care at all. It describes the significant change needed in service system design and delivery, and treatment of people with disability by health professionals.

Chapter 5 looks at the use of restrictive practices. Many people with disability are subjected to seclusion or to mechanical, chemical or physical restraint. Restrictive practices can cause lasting physical and mental harm and they are not always used as a last resort. The overuse and inappropriate use of restrictive practices is a denial of autonomy and dignity for the people subjected to them. We recommend reforms to reduce and eliminate the use of restrictive practices.

Chapter 6 addresses the issue of involuntary sterilisation. Involuntary sterilisation is an irreversible surgical procedure that permanently prevents reproduction – performed without full, free and informed consent. This chapter looks at the circumstances in which involuntary sterilisation is legal in Australia and what we have heard about this issue during this inquiry. It recommends reforms to prohibit non-therapeutic procedures.

Recommendations

Recommendation 6.1 A national plan to promote accessible information and communications

The Australian Government and state and territory governments should develop and agree on an Associated Plan in connection with Australia's Disability Strategy 2021–2031 to improve the accessibility of information and communications for people with disability. The Associated Plan should be co-designed with people with disability and their representative organisations. It should be finalised by the end of 2024.

The Associated Plan should:

- consolidate and build on existing initiatives and commitments by governments
- recognise the diversity of people with disability and the many formats and languages that people may require information to be provided in
- consider the roles of various stakeholders, including the Australian Government, state and territory governments, disability service providers, disability representative organisations and organisations representing people from culturally and linguistically diverse backgrounds
- focus, in the first instance, on information and communications about preparing for and responding to emergencies and natural disasters, and public health
- include targeted actions to ensure access to information and communications for people with disability in the criminal justice system; supported accommodation, including group homes; Australian Disability Enterprises; and day programs
- identify and allocate appropriate funding and resources for delivery
- include mechanisms for review and public reporting of progress made against the Associated Plan.

Recommendation 6.2 Increase the number of Auslan interpreters

The Australian Government and state and territory governments, through the Disability Reform Ministerial Council, should commission the development of a workforce strategy to increase the number and quality of Auslan interpreters.

The strategy should:

- be based on a robust demand-supply analysis to quantify the current gaps and shortages in interpreting services. This includes analysis of qualifications, specialisations, geographic coverage, and the availability and use of face-to-face interpreting and Video Remote Interpreting
- include costed initiatives to:
 - increase the number of Auslan interpreters, including the provision of scholarships and stable ongoing employment opportunities, particularly in under-served areas
 - support specialisations in health, legal and other critical sectors (including minimum qualifications)
 - provide ongoing professional development and industry standards to support a high-quality interpreter workforce
 - increase and retain Auslan interpreters who are First Nations or from culturally and linguistically diverse backgrounds
 - raise awareness and promote pathways to becoming an Auslan interpreter.

The strategy should be developed by September 2024, and implementation of the strategy should begin by January 2025.

Recommendation 6.3 Access to appropriately skilled and qualified interpreters

The Australian Government, the National Accreditation Authority for Translators and Interpreters (NAATI) and the National Disability Insurance Agency (NDIA) should take steps to ensure people with disability have access to appropriately skilled and qualified interpreters as needed.

Training for interpreters

NAATI should require interpreters to complete training in disability awareness before receiving accreditation and as part of their ongoing professional development to maintain accreditation.

Interpreters in disability service provision

The NDIA should:

- ensure staff are aware of the NDIA's Practice Guide on Accessible Communication and the provisions of the Practice Guide for Aboriginal and Torres Strait Islander planning support relating to interpreters and translation
- provide training for staff on how to arrange and work with an interpreter.

The Minister for the National Disability Insurance Scheme (NDIS), in consultation with states and territories, should:

- amend the *National Disability Insurance Scheme (Provider Registration and Practice Standards) Rules 2018* (Cth) to introduce a standard on effectively working with interpreters
- amend the *National Disability Insurance Scheme (Quality Indicators for NDIS Practice Standards) Guidelines 2018* (Cth) to include indicators relevant to the standard on working effectively with interpreters, including that providers have relevant policies and procedures in place.

The NDIS Quality and Safeguards Commission should amend the NDIS Workforce Capability Framework to provide that the Communicate Effectively Core Capability for Advanced Support Work explicitly includes working with interpreters.

Recommendation 6.4 Terms and definitions in guardianship and administration legislation

- a. States and territories should amend their guardianship and administration legislation to:
 - include the terms ‘support order’, ‘support agreement’ and ‘supported persons’
 - remove the terms ‘guardianship order’ and ‘administration order’ or ‘financial management order’, and replace these with ‘representative order’
 - remove the terms ‘guardian’ and ‘administrator’ or ‘financial manager’, and replace these with ‘representative’
 - remove the term ‘enduring guardian’ and replace this with ‘enduring representative’
 - remove the terms ‘enduring guardianship’ and ‘enduring power of attorney’, and replace these with ‘enduring representation agreement’
 - remove the terms ‘decision-making capacity’, ‘capacity’ and ‘mental incapacity’, and replace these with ‘decision-making ability’.
- b. The new and replacement terms should be defined consistently with the definitions provided in Table 6.2.11.
- c. States and territories should amend the title of their guardianship and administration legislation to refer to decision-making. For example, ‘Supported and represented decision-making Act’ or ‘Decision-making Act’.

Recommendation 6.5 Objects of guardianship and administration legislation

States and territories should review and reform their guardianship and administration legislation to include a statement of statutory objects which:

- recognises and promotes the rights of people with disability consistent with the *Convention on the Rights of Persons with Disabilities (CRPD)*
- includes the text of article 12 of the *CRPD*
- recognises the role of support to enable people who may require support to make, participate in and implement decisions that affect their lives.

Recommendation 6.6 Supported decision-making principles

- a. States and territories which have not already done so should review and reform their guardianship and administration legislation to include the following supported decision-making principles. The legislation should oblige all persons exercising powers, carrying out functions or performing duties under the legislation to have regard to the principles.

Principle 1 – Recognition of the equal right to make decisions

All people have an equal right to make decisions that affect their lives and to have those decisions respected.

Principle 2 – Presumption of decision-making ability

All people must be presumed to be able to make decisions.

Principle 3 – Respect for dignity and dignity of risk

All people must be treated with dignity and respect and supported to take risks to enable them to live their lives the way they choose, including in their social and intimate relationships.

Principle 4 – Recognition of informal supporters and advocates

The role of informal supporters, support networks and advocates who provide support for decision-making should be acknowledged and respected.

Principle 5 – Access to support

People who may require supported decision-making should be provided with equitable access to appropriate support to enable the person, as far as practicable in the circumstances, to:

- make and participate in decisions affecting them
- communicate their will and preferences
- develop their decision-making ability.

Principle 6 – Decisions directed by will and preferences

The will and preferences of people who may require supported decision-making must direct decisions that affect their lives.

Principle 7 – Inclusion of safeguards

There must be appropriate and effective safeguards where people may require supported decision-making, including to prevent abuse and undue influence.

Principle 8 – Co-designed processes

People with disability, in particular people with cognitive disability, their supporters and representative organisations, should be involved in the development and delivery of policies and practices on supported decision-making.

Principle 9 – Recognition of diversity

The diverse experiences, identities and needs of people who may require supported decision-making must be actively considered.

Principle 10 – Cultural safety

First Nations people and culturally and linguistically diverse people with disability are entitled to supported decision-making that is culturally safe, sensitive and responsive. This includes recognising the importance of maintaining a person's cultural and linguistic environment and set of values.

- b. The Australian Government and state and territory governments should also take steps to review and reform other laws concerning individual decision-making to give legislative effect to the supported decision-making principles.

Recommendation 6.7 Decision-making ability

States and territories should review and reform their guardianship and administration legislation to:

- ensure consistency with Principle 2 in Recommendation 6.6 that all people should be presumed to be able to make decisions
- provide that this presumption cannot be rebutted solely on the basis that a person has a disability

- require that anyone responsible for deciding whether the presumption has been rebutted that a person has decision-making ability for the relevant decision, must consider:
 - the supports available to the person, including the quality of existing support relationships
 - that decision-making ability is specific to the decision being made
 - the nature and complexity of the specific decision to be made
 - the views of the person and, with their consent, the views of family and informal supporters who have significant involvement in the person's life.

Recommendation 6.8 Formal supporters

States and territories should introduce into guardianship and administration legislation provisions to enable statutory and personal appointments of one or more supporters for personal and financial matters, following the approach taken by Victoria in Part 4 of the *Guardianship and Administration Act 2019* (Vic) and Part 7 of the *Powers of Attorney Act 2014* (Vic). This includes provisions on:

- appointment of supporters
- role, powers and duties of supporters
- safeguards in relation to supports
- review and revocation of support agreements and orders.

Recommendation 6.9 Representatives as a last resort

States and territories should review and reform their guardianship and administration legislation to provide that representation orders should be made only as a last resort and in a way that is least restrictive of a person's rights, autonomy and actions, as practicable in the circumstances. The reforms should include:

- a. the repeal of provisions authorising plenary representation orders
- b. a requirement that the relevant tribunal should make an order appointing a representative only if satisfied that:
 - the proposed represented person does not have decision-making ability for one or more decisions

- the order is necessary, taking into account:
 - the will and preferences of the proposed represented person
 - the availability and suitability of less intrusive and restrictive measures, including formal and informal support arrangements, negotiation and mediation
 - the order will promote the person's personal and social wellbeing
- c. a provision that the tribunal must take into account, in deciding whether a person (other than a public official) is suitable for appointment as a representative:
- the will and preferences of the proposed represented person
 - the nature of the relationship between the proposed representative and the proposed represented person
 - whether the proposed representative is likely to act honestly, diligently and in good faith
 - whether the proposed representative has or may have a conflict of interest in relation to any of the decisions referred to in the order
- d. a prohibition on a representation order made in the absence of the proposed represented person, unless the tribunal is satisfied that either:
- the represented person does not wish to attend the hearing in person
 - the personal attendance of the represented person at the hearing is impracticable or cannot reasonably be arranged
- e. a requirement that when considering whether a support or representation order should be made for a First Nations person, the tribunal should take into account:
- the likely impact of the order on the person's culture, values, beliefs (including religious beliefs) and linguistic environment
 - the likely impact of the order on the person's standing or reputation in their community
 - any other considerations pertaining to the person's culture
- f. provisions on the review and revocation of representation orders, including that:
- a representation order lapses on the expiration of three years after the date on which it is made, unless the tribunal has specified an expiry date (earlier than three years) in the order or the order is renewed
 - a tribunal must conduct a review of a representation order at least once within each three-year period after making the order

- when reviewing an order, the tribunal should consider:
 - whether the order is still necessary, considering the factors listed in b.
 - whether the representative is still eligible and suitable
 - whether the representative is meeting their responsibilities and carrying out their required functions.

Recommendation 6.10 Decision-making process

States and territories should review and reform their guardianship and administration legislation to include a decision-making process that appointed supporters and representatives are required to follow.

The decision-making process for both supporters and representatives should involve:

- supporting the person to express their will and preferences
- assisting the person to develop their own decision-making ability.

The decision-making process for representatives should also include the following steps and considerations:

- the person's will and preferences must be given effect
- where the person's current will and preferences cannot be determined, the representative must give effect to what they believe the person's will and preferences are likely to be, based on all the information available
- if it is not possible to determine what the person would likely want, the representative must act to promote and uphold the person's personal and social wellbeing with the least possible restriction on their dignity and autonomy
- a representative may override the person's will and preferences only where necessary to prevent serious harm. In these circumstances, the representative must act to promote and uphold the person's personal and social wellbeing with the least possible restriction on their dignity and autonomy.

Recommendation 6.11 Guidelines on maximising participation

- a. The Australian Guardianship and Administration Council should update the *Guidelines for Australian Tribunals: Maximising the participation of the Person in guardianship proceedings* to align with our recommendations on guardianship and supported decision-making (see in particular Recommendations 6.4–6.10 and 6.19).
- b. The guardianship division or list in each state and territory tribunal should consider adopting, through practice directions or other appropriate means, the updated *Guidelines for Australian Tribunals: Maximising the participation of the Person in guardianship proceedings*.

Recommendation 6.12 Public disclosure and confidentiality restrictions

States and territories should amend their guardianship and administration laws or tribunals acts to:

- repeal provisions prohibiting publication of material identifying a party to the proceedings as the default position
- empower the tribunal to make an order prohibiting publication of material identifying the party to the proceedings if the circumstances justify such an order, taking into account the will and preferences of that party.

Recommendation 6.13 Information and education on supported decision-making

- a. States and territories should ensure that, where legislation to this effect is not already in place, the functions of public advocates and public guardians include providing information, education and training on supported decision-making to people requiring supported decision-making and their families, private supporters and representatives (present or prospective), disability service providers, public agencies, the judiciary, tribunal members and legal representatives.
- b. States and territories should ensure that, where legislation to this effect is not already in place, public advocates and public guardians are empowered to provide advice and assistance to people who may require decision-making support, including in relation to applications for support and representation orders.

Recommendation 6.14 Systemic advocacy to promote supported decision-making

States and territories should ensure that, where this is not already the case, a statutory body has a function to undertake systemic advocacy to promote supported decision-making. This function should include:

- monitoring, investigating, researching, reporting, making recommendations and advising on any aspect of relevant decision-making legislation
- encouraging the development and improvement of programs, services and facilities that promote the autonomy of people with disability
- supporting organisations that undertake advocacy and education on supported decision-making.

Recommendation 6.15 Updating the national standards for public advocates, public guardians and public trustees

Public advocates, public guardians and public trustees, through the Australian Guardianship and Administration Council, should update the *National Standards of Public Guardianship* and *National Standards for Financial Managers* to:

- include the supported decision-making principles
- align with reforms to state and territory guardianship and administration legislation that give effect to Recommendations 6.4–6.10
- amend the relevant standards to provide that public officials acting as representatives should have frequent meetings and ongoing, accessible communication with the represented person to get to know the person and develop a trusted relationship. Meetings should take place in line with a represented person's preferences as to format and attendees, wherever practicable
- amend the relevant standards to recognise the importance of ensuring all engagement with First Nations and culturally and linguistically diverse people is culturally safe and responsive and that appropriate training for staff is provided to enable them to do so
- amend the relevant standards to recognise the importance of public officials acting as representatives facilitating connections between a represented person and advocates and informal supporters.

Recommendation 6.16 Financial skills development programs

- a. All public trustees should offer a financial skills development program to people under a representation order appointing the public trustee as a representative. The program should promote financial independence and:
 - be developed in partnership with representative organisations of people with disability, including organisations representing people with intellectual disability, and financial counselling community support organisations
 - incorporate broad eligibility criteria
 - be actively promoted, especially among people entering administration.
- b. Upon successful completion of the program, public trustees should support a person to apply for a review of their order. If a person is not eligible for the program, the public trustee must advise them of their right to apply to the relevant tribunal for review of their order.
- c. Public trustees should report annually on the number of people who have participated in the program, the number who have completed it and the number who have subsequently transitioned out of administration arrangements.

Recommendation 6.17 Transparency of public trustee fees and charges

Public trustees in each state and territory should:

- publish accessible information about the services they provide to people under administration orders, the fees and charges applicable for those services and the ways in which fees are calculated for each individual
- on appointment, annually and following any significant change to a person's circumstances, send to people under administration orders individualised and accessible information detailing the services they will receive and the fees for those services.

Recommendation 6.18 Review of public trustees' fees and charges

State and territory governments should ensure that public trustees' fees and charges have been independently reviewed since 2019. Where such a review has not been conducted since this time, state and territory governments should arrange a comprehensive review of the fees and charges payable by people under administration orders to the public trustee in their jurisdiction. The reviews should make recommendations to ensure fees and charges are fair and equitable for all people under administration orders.

Recommendation 6.19 Data collection on support and representation arrangements

The Australian Government and states and territories should develop and implement a national approach to collecting and publishing de-identified data on support and representation arrangements, led by the Australian Institute of Health and Welfare.

The national approach should consistently use definitions of 'disability', 'representation' and 'support' arrangements proposed in this *Final report*, and should employ methodologies which enable reporting on comparisons across jurisdictions and trends over time.

The national approach should include collection and publication of data on:

- numbers of formally appointed representatives and supporters, disaggregated appropriately
- the extent to which people with disability who are the subject of the proceedings participate in the proceedings and the manner in which they participate (for example, in person or via alternative technological means)
- numbers of representative agreements commenced, terminated, revoked, varied or reviewed
- the extent to which people with disability who are the subject of the proceedings are legally represented.

The data should identify, to the greatest extent practicable, types of impairment, age, First Nations people with disability, culturally and linguistically diverse people with disability, LGBTIQ+ people with disability, women with disability and National Disability Insurance Scheme participants.

Recommendation 6.20 Interpretative declaration

Commissioners Bennett, Galbally, Mason and McEwin recommend the Australian Government withdraw its interpretative declaration in relation to article 12 of the *Convention on the Rights of Persons with Disabilities*.

Recommendation 6.21 Additional funding for advocacy programs

- a. For the financial years 2024–25 and 2025–26, the Australian Government should commit additional funding of:
 - \$16.6 million per annum for the National Disability Advocacy Program
 - \$20.3 million per annum for the National Disability Insurance Scheme Appeals Program.

These amounts should be indexed to maintain their value in real terms from year to year.

- b. From 1 July 2026, the Australian Government should ensure long-term and stable funding for national disability advocacy programs to meet demand. This should be informed by improved data in line with Recommendation 6.22.
- c. From at least 1 July 2026, state and territory governments should ensure long-term and stable funding for disability advocacy programs in their jurisdictions to meet demand. This should be informed by improved data in line with Recommendation 6.22.

Recommendation 6.22 Improved data collection and reporting on met and unmet demand for disability advocacy

The Australian Government and state and territory governments should improve data collection and reporting on met and unmet demand for disability advocacy within their jurisdiction.

At a minimum, this data should:

- be collected and published on an annual basis
- include demographic indicators that show geographic location, First Nations and culturally and linguistically diverse status
- identify, where possible, whether a request for disability advocacy is from or concerns a person with disability who lives in supported accommodation or is in prison or juvenile detention.

This data should be collected and reported on an ongoing basis.

The Australian Government and state and territory governments should include data collection and reporting as a priority work area in the Disability Advocacy Work Plan associated with the 2023–2025 National Disability Advocacy Framework, and progress this as part of future National Disability Advocacy Frameworks or equivalents.

The Australian Government and state and territory governments should work together to ensure consistent definitions and methodologies allowing comparisons across jurisdictions and trends over time.

Publication of the data should commence no later than 1 July 2026.

Recommendation 6.23 Culturally safe disability advocacy

The Disability Advocacy Work Plan associated with the 2023–2025 National Disability Advocacy Framework should be amended to include priority work areas on increasing culturally appropriate and accessible advocacy services for people with disability from culturally and linguistically diverse backgrounds and LGBTIQ+ people with disability. Efforts under these priority work areas, and the priority work area on increasing culturally appropriate and accessible advocacy services for First Nations people with disability, should include training led by First Nations, culturally and linguistically diverse, and LGBTIQ+ people with disability and their representative organisations.

This work should be progressed as part of future National Disability Advocacy Frameworks or equivalents.

Recommendation 6.24 Improve implementation planning and coordination for the cognitive disability health capability framework

The Australian Government Department of Health and Aged Care should:

- expand the role of the Intellectual Disability Education and Training Expert Advisory Group to develop an implementation plan for the cognitive disability health capability framework, including key steps for embedding the capabilities from the framework in curricula in education and training programs for health practitioners across all training stages
- develop a monitoring and evaluation framework to coordinate and measure delivery of the expanded capability framework and its implementation.

Recommendation 6.25 Expand the scope of health workforce capability development to include all forms of cognitive disability at all stages of education and training

The Australian Government Department of Health and Aged Care should:

- immediately expand the scope of the work on an intellectual disability health capability framework and associated resources to address all forms of cognitive disability, to apply at all stages of education and training. This expansion should include autism-specific content, and address specific healthcare issues for people with learning disability, dementia and acquired brain injury.
- allocate additional funding to support the expanded scope of health workforce capability development.

Recommendation 6.26 Expand the role of the Health Ministers Meeting to monitor health workforce capability development

The Health Ministers Meeting should expand its role in monitoring progress of the intellectual disability health capability framework to encompass the expanded capability framework proposed in Recommendation 6.25. This should include annual reporting to the Health Ministers Meeting on the progress of actions.

Recommendation 6.27 Establish regular progress reporting by accreditation authorities

Accreditation authorities for registered health professions and the peak professional bodies for non-registered health professions should:

- a. review and amend accreditation standards and evidence requirements where necessary to address whether cognitive disability health is sufficiently covered. If it is not, they should amend their accreditation standards or evidence requirements (as the case may be) accordingly.
- b. encourage or mandate education providers to develop specific cognitive disability health curriculum content and deliver such content using inclusive teaching practices, involving people with cognitive disability where possible.

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- c. report annually to the Australian Government Department of Health and Aged Care on their progress in implementing this recommendation. Where accreditation authorities have only recently undertaken their five-yearly review, annual reporting should include progress on implementation planning to address this recommendation pending the next scheduled review.

Recommendation 6.28 Improve access to clinical placements in disability health services

The Australian Government Department of Health and Aged Care should make improved access to clinical placements in disability health services an immediate priority, including by:

- exploring increased opportunities for student learning and development in cognitive disability health, including as part of interprofessional teams, with education providers and clinical placement providers.
- considering mechanisms to enhance funded supervised clinical and work-based training placements to train students in providing quality health care to people with cognitive disability. This should include enhanced financial support for clinical placement and supervision in community settings.

Recommendation 6.29 Improve specialist training and continuing professional development in cognitive disability health care

- a. The Royal Australasian College of Physicians, Royal Australian and New Zealand College of Psychiatrists, Australian and New Zealand College of Anaesthetists, Royal Australian College of General Practitioners, Australasian College of Emergency Medicine and Australian College of Rural and Remote Medicine should each:
- develop specialised training content in cognitive disability health for different areas of specialisation, building on the capability framework and the core set of learning resources, so that future specialists can develop skills and competencies in cognitive disability health
 - expand and promote pathways for sub-speciality training in cognitive disability health.

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- b. These groups, as well as the Australian Dental Association and professional bodies responsible for continuing professional development (CPD) in the nursing and allied health professions should each:
- review CPD programs in their respective health discipline or specialty to determine whether CPD for the provision of health care to people with cognitive disability, including intellectual and/or developmental disabilities, should be enhanced
 - promote the development of CPD opportunities on the provision of health care to people with cognitive disability, including intellectual and/or developmental disabilities
 - raise awareness of such CPD opportunities among members.
- c. The Australian Government Department of Health and Aged Care should reprioritise the National Roadmap for Improving the Health of People with Intellectual Disability action to embed training and CPD within all specialist training programs from a medium-term action (four to six years), to a short-term action (one to three years).

Recommendation 6.30 Expand the scope of the National Centre of Excellence in Intellectual Disability Health

The Australian Government Department of Health and Aged Care should expand the remit of the National Centre of Excellence in Intellectual Disability Health to include autism and other forms of cognitive impairment.

Recommendation 6.31 Embed the right to equitable access to health services in key policy instruments

- a. The Australian Commission on Safety and Quality in Health Care should:
- amend the Australian Charter of Healthcare Rights to incorporate the right to equitable access to health services for people with disability and align with the scope of this proposed right in the Disability Rights Act recommended in Volume 4, *Realising the human rights of people with disability*

- review and revise the National Safety and Quality Health Service Standards and the National Safety and Quality Primary and Community Healthcare Standards to provide for the delivery of safe and high-quality health care for people with disability and align with the scope of the proposed right to equitable access to health services in the Disability Rights Act recommended in Volume 4
 - as part of this review, consider how the national standards support equal access to health services for people with disability throughout life, including (but not limited to) prevention and health promotion, diagnosis and early intervention and rehabilitation services.
- b. The Australian Government Department of Health and Aged Care and state and territory counterparts should review all policies and protocols to ensure people with disability are permitted to be accompanied by a support person in any health setting. This should apply at all times, including when in-person healthcare restrictions are in place, such as during COVID-19.

Recommendation 6.32 Increase capacity to provide supports and adaptations through improved guidance, funding and accessible information

The Australian Government and state and territory governments, in consultation with people with disability, should:

- a. identify and publish a list of frequently needed adaptations and supports (including communication supports) to enable people with disability to receive high-quality health care in all publicly funded settings. Adaptations and supports may need to be tailored to individual needs and additional supports may be required. These should include:
- environmental modifications and aids to reduce sensory loads, such as dimmer lighting, reduced background noise and noise-cancelling headphones
 - preparatory action to familiarise the person with disability with clinical environments, such as hospital tours and animated videos
 - different modes of service delivery, such as home visits, and taking a forward-looking approach to minimise distress associated with certain procedures – for instance, taking extra blood to reduce the need for additional blood draws, or undertaking multiple procedures at once if sedation is required to decrease the number of hospital visits
 - novel and flexible approaches to pre-medication, including sedation, to reduce distress and anxiety before critical medical procedures.

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- b. review hospital (admitted and non-admitted care) and primary health care funding models to ensure these adaptations and supports can be implemented in all relevant settings.
 - c. disseminate information about the provision of adaptations and supports in a range of accessible formats.

Recommendation 6.33 Develop specialised health and mental health services for people with cognitive disability

State and territory governments should establish and fund specialised health and mental health services for people with cognitive disability to provide:

- specialist assessment and clinical services, including preventive medicine, for people with cognitive disability and complex or chronic health and mental health needs
- training and support for health providers to build their capacity to provide safe, high-quality health care to people with cognitive disability.

These services should be delivered through a model that includes:

- specialist roles and multi-disciplinary teams embedded in local health service delivery
- statewide specialised services that can be accessed by people with cognitive disability and health professionals regardless of their location
- participation in a national network of specialised disability health and mental health services
- evaluation of the impact of specialised services and publication of evaluation findings.

Planning to implement specialised services in each jurisdiction should begin as soon as practicable and take into account existing services and needs in each jurisdiction. These changes should be introduced by September 2026.

Recommendation 6.34 Introduce disability health navigators to support navigation of health care for people with disability

Through the Health Ministers Meeting, the Australian Government and state and territory governments should:

- a. jointly fund a national workforce of 'disability health navigators' to support people with cognitive disability and complex health needs access health services and to embed safe, accessible and inclusive practice in everyday health service provision
- b. develop a national evaluation framework to assess the impact of disability health navigators and share lessons learned across jurisdictions. Evaluation findings should be published.

Recommendation 6.35 Legal frameworks for the authorisation, review and oversight of restrictive practices

- a. States and territories should ensure appropriate legal frameworks are in place in disability, health, education and justice settings, which provide that a person with disability should not be subjected to restrictive practices, except in accordance with procedures for authorisation, review and oversight established by law.
- b. The legal frameworks should incorporate the following requirements, appropriately adapted to sector-specific contexts:
 - Restrictive practices should only be used:
 - as a last resort, in response to a serious risk of harm to a person with disability or others, and only after other strategies, including supported decision-making, have been explored and applied
 - as the least restrictive response possible to ensure the safety of the person with disability or others
 - to the extent necessary to reduce the risk of harm and proportionate to the potential negative consequences from the use of restrictive practices
 - for the shortest time possible.
 - Decisions to authorise restrictive practices should be subject to independent review.
 - The use of restrictive practices should be subject to independent oversight and monitoring.

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- c. The legal frameworks should set out the powers and functions of a Senior Practitioner for restrictive practices in disability service provision (or equivalent authority). These powers and functions should include:
- promoting the reduction and elimination of the use of restrictive practices
 - protecting and promoting the rights of people with disability subjected to restrictive practices
 - developing and providing information, education and advice on restrictive practices to people with disability, their families and supporters, and the broader community
 - considering applications to use restrictive practices in disability service settings and authorising their use according to procedures consistent with the Draft Principles for Consistent Authorisation
 - developing guidelines and standards, and providing expert advice, on restrictive practices and behaviour support planning
 - receiving complaints about the use of restrictive practices and the quality of behaviour support planning
 - investigating the use of restrictive practices and the quality of behaviour support planning, either in response to complaints or of its own motion
 - acting in response to complaints and investigations where appropriate.

Recommendation 6.36 Immediate action to provide that certain restrictive practices must not be used

State and territory governments should immediately:

- Adopt the list of prohibited forms of restrictive practices agreed by the former Disability Reform Council in 2019 and provide that the use of seclusion on children and young people is not permitted in disability service settings.
- Provide that the following are not permitted in health and mental health settings:
 - using seclusion and restraint as a means to reduce behaviours not associated with immediate risk of harm
 - using seclusion and restraint as a form of discipline, punishment or threat
 - restrictive practices that involve or include deliberate infliction of pain to secure compliance

- using prone or supine holds, using any restraint intended to restrict or affect respiratory or digestive function, or forcing a person's head down to their chest
- secluding a person who is also mechanically restrained
- secluding a person who is actively self-harming or suicidal
- using metal handcuffs or hard manacles as a form of mechanical restraint (unless under police or other custodial supervision while in the health facility)
- vest restraints for older people
- neck holds
- drugs, or higher doses of drugs, that create continuous sedation to manage behaviour
- seclusion of children and young people.
- Provide that the following are not permitted in education settings:
 - the use of restrictive practices:
 - as a form of discipline, punishment or threat
 - as a means of coercion or retaliation
 - in response to property destruction
 - for reasons of convenience
 - life threatening physical restraints, including physical restraints that restrict a student's breathing or harm the student by:
 - covering the student's mouth or nose, or in any way restricting breathing
 - taking the student to the ground into the prone or supine position
 - causing hyperextension or hyperflexion of joints
 - applying pressure to the neck, back, chest or joints
 - deliberately applying pain to gain compliance
 - causing the student to fall
 - having a person sit or kneel on the student
 - chemical restraints
 - mechanical restraints
 - clinical holding:

- as a behaviour support strategy
- to enforce the compliance of a student in undertaking personal care that is non-urgent and does not present a risk to the student
- to punish a student
- denial of key needs, such as food and water.

Recommendation 6.37 Data collection and public reporting on psychotropic medication

The NDIS Quality and Safeguards Commission, the Australian Commission on Safety and Quality in Health Care and the Aged Care Quality and Safety Commission should:

- publish joint annual progress reports on implementation of measures under the Joint statement on the inappropriate use of psychotropic medicines to manage the behaviours of people with disability and older people
- commission an independent evaluation of these measures to determine whether they have resulted in a reduction in the use of psychotropic medicines against people with cognitive disability. The evaluation should be co-designed with people with cognitive disability and their representative organisations and its results should be publicly reported.

Recommendation 6.38 Strengthening the evidence base on reducing and eliminating restrictive practices

The National Disability Research Partnership should commission a longitudinal study of the impact of positive behaviour support and other strategies to reduce and eliminate restrictive practices. This study should:

- be co-designed with people with disability and relevant experts and professionals from the disability, health, education and justice sectors, to ensure the findings are relevant across a range of settings
- include the experiences and identify the intersecting needs of a broad range of people with disability, such as First Nations people with disability, LGBTIQ+ people with disability, and culturally and linguistically diverse people with disability.

Upon completion, the findings of the study should be made publicly available. Interim findings should be published at regular intervals.

Recommendation 6.39 Improving collection and reporting of restrictive practices data

The Australian Institute of Health and Welfare should work with state and territory governments to develop consistent data definitions and collection methods on restrictive practices across all jurisdictions, and align reporting periods. These definitions and collection methods should be finalised by the end of 2024.

Using consistent definitions and collection methods, state and territory governments should collect and publish data on the use of restrictive practices in health, education and justice settings. This data should be collected and published on an annual basis, with publication commencing by the end of 2025 at the latest. Data should identify, to the greatest extent practicable:

- restraint type, including chemical, physical, mechanical, environmental and seclusion
- disability status
- types of impairment
- age
- gender
- First Nations people
- culturally and linguistically diverse people
- people who identify as LGBTIQ+.

Recommendation 6.40 Targets and performance indicators to drive the reduction and elimination of restrictive practices

The Australian Government and state and territory governments should establish sector-specific targets and performance indicators to drive the reduction and elimination of restrictive practices over time. This should be at both the national and state and territory levels for disability, health, education and justice settings. These targets and performance indicators should be established by 1 July 2025 at the latest.

Recommendation 6.41 Legislative prohibition of non-therapeutic sterilisation

- a. All jurisdictions should amend or enact legislation prohibiting non-therapeutic procedures resulting in permanent sterilisation of people with disability, except where:
 - there is a threat to the life of the person with disability were the procedure not performed or
 - the person with disability is an adult and has given voluntary and informed consent to the procedure, with support for decision-making if required.
- b. All jurisdictions should amend or enact relevant legislation in accordance with paragraph a. by the end of 2024.
- c. The Australian Guardianship and Administrative Council (AGAC) should expand its annual collation and publication of data on the sterilisation of people with disability. This data should include the number of applications, reasons for applications, reasons for the outcomes of applications and the number of approvals to conduct a sterilisation procedure.

Where this does not already occur, the data should be collected and provided to AGAC annually by:

- the Federal Circuit and Family Court of Australia
- state and territory superior courts
- state and territory guardianship and administration bodies.

The data should be de-identified, as appropriate. It should be disaggregated, to the greatest extent possible, by:

- disability status
 - types of impairment
 - age
 - gender
 - First Nations people
 - culturally and linguistically diverse people
 - people who identify as LGBTIQ+.
- d. A review of legislation enacted or amended according to paragraph a. of this recommendation should be conducted every five years, in light of the data published according to paragraph c. This review should aim to strengthen protections for people with disability and avoid consequences which hamper reproductive autonomy.

Endnotes

- 1 Julian Laurens, Shona Bates, Rosemary Kayess & Karen R Fisher, for the Australian Government Department of Social Services, *Good Practice in Supported Decision-making for People with Disability*, Final report, June 2021.
- 2 *Letters Patent* (Cth), 4 April 2019, recitals.
- 3 *Convention on the Rights of Persons with Disabilities*, opened for signature 30 March 2007, 2515 UNTS 3 (entered into force 3 May 2008), art 3(a).
- 4 Annie Norton, Submission, 1 March 2022, SUB.001.01628, p 1.
- 5 Exhibit 31-003, 'Statement of Mr Gerard Quinn', 12 December 2022, pp 8–9; Transcript, Gerard Quinn, Public hearing 31, 12 December 2022, P-53 [41–48].
- 6 Transcript, Gerard Quinn, Public hearing 31, 12 December 2022, P-54 [1–3].
- 7 Anna Arstein-Kerslake, Erin O'Donnell, Rosemary Kayess & Joanne Watson, 'Relational personhood: a conception of legal personhood with insights from disability rights and environmental law', (2021), vol 30 (3), *Griffith Law Review*, pp 533, 541. See also, Lauren Davy and Celia Green, 'The Right to Autonomy and the Conditions that Secure It: The Relationship Between the UNCRPD and Market-Based Policy Reform', (2022), *Disability Law and Human Rights*, p 130.
- 8 Shane Clifton, *Hierarchies of power: disability theories and models and their implications for violence against, and abuse, neglect, and exploitation of, people with disability*, Report prepared for the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, October 2020, p 26.
- 9 Shane Clifton, *Hierarchies of power: disability theories and models and their implications for violence against, and abuse, neglect, and exploitation of, people with disability*, Report prepared for the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, October 2020, p 25.
- 10 Catalina Devandas-Aguilar, Special Rapporteur on the rights of persons with disabilities, *Report of the Special Rapporteur on the rights of persons with disabilities: Access to rights-based support for persons with disabilities*, UN HRC, 34th sess, Agenda Item 3, UN Doc A/HRC/34/58, (20 December 2016), p 5.

1. Accessible information and communications

Key points

- People with disability have a right to access information and communications on an equal basis with others. Information and communications are accessible if people with disability can use and understand them in a way that suits their needs.
- Accessible information and communications are a critical safeguard against violence, abuse, neglect and exploitation. They are necessary for people with disability to exercise autonomy.
- People with disability often find information and communications inaccessible, in contexts including health care, disability service settings like group homes, education, employment and prisons. We heard about the inaccessibility of information about a range of vital topics, including public health, COVID-19 and other emergencies, and sexuality and relationships.
- First Nations people with disability and people with disability from culturally and linguistically diverse backgrounds can face additional barriers to accessing the information and communications they need.
- There are a number of initiatives and commitments to provide accessible information in Australia, but more work is needed. We recommend a unified approach that brings together relevant players and builds on existing work.
- Interpreters also play a critical role in supporting people with disability to participate in conversations and decisions that affect them.
- However, there is a shortage of Auslan interpreters, and this can prevent Deaf people from accessing critical services. A national workforce strategy is needed to address this shortage.
- There is also a shortage of interpreters of both First Nations sign languages and First Nations spoken languages. People with disability from culturally and linguistically diverse backgrounds can also find it difficult to access spoken language interpreters. This can make it much harder to access the services they need. Training and practice change are needed to ensure interpreters understand disability and service providers know when and how they should work with interpreters.

1.1. Introduction

This chapter examines the accessibility of information and communications for people with disability. Information and communications are accessible if they are presented in ways that people with disability can fully understand and use. Accessible information and communications include the provision of accessible written information, such as pre-recorded Auslan videos that translate a fact sheet, or Easy Read materials. They also include 'real-time' one-way communications, such as Auslan interpreters during emergency broadcasts.

Clear, timely and accessible information and communications can help safeguard people with disability against violence, abuse, neglect and exploitation. People with disability need to be able to understand information that government agencies and service providers give them and communicate their views and preferences.

This chapter begins by examining different forms of accessible information and communications. It summarises Australia's obligations under international and domestic law to provide accessible information. It considers the barriers to accessible information and communications in a range of settings and contexts, and the negative impacts of being unable to access information or to communicate. It looks at existing initiatives to provide accessible information, commitments to improve these measures and the need for further work. It recommends a unified approach to accessible information and communications across Australia.

The chapter then focuses on interpreter services. In addition to accessible information and communications, people with disability may also need support to ensure they can share their views and preferences in conversations on matters that affect them. This support may include interpreters, discussed later in this chapter. It may also include support for decision-making, which is discussed in Chapter 2 of this Volume.

The chapter looks specifically at the role and shortage of Auslan interpreters. It recommends a workforce strategy to increase their number and skills. It considers the range of languages of people with disability, including First Nations people with disability and culturally and linguistically diverse people with disability. It highlights the importance of spoken language interpreters with appropriate skills and understanding of disability, and makes a recommendation to increase the skills and accessibility of spoken language interpreters, including in disability services.

As discussed in Volume 4, *Realising the human rights of people with disability*, the Royal Commission recommends the proposed Disability Rights Act requires Commonwealth entities to:

- ensure that their communications are provided in at least two accessible formats when:
 - publishing public information
 - consulting or engaging with people with disability
- provide (arrange and fund) an interpreter when required by a person with disability who is accessing or using their services or engaging with their statutory functions.

The recommendations in this chapter complement the proposed rights and duties in the Disability Rights Act regarding accessible information and interpreters.

1.2. Accessible communication and information

Dr Ariella Meltzer, Research Fellow at the Centre for Social Impact, University of New South Wales, gave evidence at Public hearing 5, ‘Experiences of people with disability during the ongoing COVID-19 pandemic’. Dr Meltzer described accessible information as ‘information which can be used and understood by people with disability due to it appropriately accommodating their support needs’.¹ Dr Meltzer told us there are different forms of accessible information:

‘Visual accessibility’ and ‘print accessibility’ means that information is accessible to people with low vision – [for example] it uses large text, wide spacing and sans serif fonts.

‘Web accessibility’ refers to information that is accessible on the internet – for example, having alternate text behind images for screen readers. Standards for web accessibility are outlined in the Web Content Accessibility Guidelines.

‘Conceptual accessibility’ is where information uses easy language and only the main points of information, so it is easy to understand. Common formats include Easy Read and Easy English, where pictures are also present to support people’s understanding of the written information.

Other examples of information accessibility include where resources are provided in Auslan and information is made in other formats that allow communication, for example, resources for users of alternative and augmentative communication systems.²

People with disability may also require information or communications to be provided through:³

- live and closed captioning
- braille
- tactile sign language and visual frame signing
- audio recordings.

Australia’s Disability Strategy 2021–2031 (ADS) recognises the importance of accessible information and communication, saying it:

is vitally important in all aspects of life. It is central to people's safety and health, to involvement in their communities, employment and education, and to using transport, banking and shopping. Provision of communication in accessible formats ([for example] Braille, Auslan, Easy Read formats) can have a positive impact on the health of and opportunities for people with disability.⁴

Responses to the *Promoting inclusion issues paper* identified accessible information and communications as a key characteristic of an inclusive society.⁵ Speech Pathology Australia emphasised:

Communication access is as important as physical access to people with disability if they are to participate fully in social, economic, sporting and community life in line with the Convention on the Rights of Persons with Disabilities.⁶

Accessible information is necessary for everyone in society, but people with disability who may face barriers to this include:

- people who are blind or have low vision
- people who are d/Deaf or hard of hearing
- people who are d/Deafblind
- people with cognitive disability.

First Nations people with disability and people with disability from culturally and linguistically diverse backgrounds may face additional barriers to accessing information and communications. The Australian Bureau of Statistics 2018 *Survey of Disability, Ageing and Carers, Australia: Summary of Findings* estimated 460,000 Australians aged 0 to 64 had some level of 'communication disability', with many more aged over 64. Communication disability ranged from those who communicated effectively using a communication aid, to those considered unable to understand or be understood.⁷

Evidence at Public hearing 29, 'The experience of violence against, abuse, neglect and exploitation of people with disability from culturally and linguistically diverse communities', showed that government services and agencies often assume their audiences have the level of English proficiency required to understand and respond to their communications. This is a significant barrier for people with disability who do not use English as their first language. We have heard in particular about language barriers in the context of the National Disability Insurance Scheme (NDIS), which we discuss further in Section 1.4.⁸

International human rights obligations

The *CRPD* and the right to access information and communications

The right to information and communications is recognised in several articles of the *Convention on the Rights of Persons with Disabilities (CRPD)*.⁹ Article 3 sets out the general principles of the *CRPD*, including:

-
- non-discrimination
 - full and effective participation and inclusion
 - accessibility.

States Parties should use the general principles set out in article 3 when giving effect to their obligations under the *CRPD*.

Articles 9 and 21 of the *CRPD* directly relate to the provision of accessible information and communication. In a report prepared for the Royal Commission assessing Australia's level of compliance with the *CRPD*, Emeritus Professor Ron McCallum AO described article 9 as a 'radical provision that seeks to cover the entire gamut of accessibility'.¹⁰ Article 9 obliges States Parties to take appropriate measures to ensure people with disability have equal access to information and communications (including information and communications technologies and systems).¹¹ In doing this, States Parties must identify and eliminate barriers to accessibility.¹²

In its *General comment no. 2 (2014) on article 9, Accessibility*, the Committee on the Rights of Persons with Disabilities (CRPD Committee) described the minimum standards and a guideline for accessibility.¹³ In the Committee's view, article 9 requires all newly designed objects and products to be fully accessible.¹⁴ However, for existing infrastructure, transportation and services, accessibility can be implemented progressively.¹⁵ The approach recognises that some rights will take time to implement depending on each State Party's economic and social capacity. States Parties may implement article 9 gradually, as long as there are definite timeframes and they allocate adequate resources to remove existing barriers.¹⁶

Article 21 has a more targeted focus on information and communication.¹⁷ It deals with two related rights:¹⁸

- freedom of expression and opinion
- the right to access information.

As Professor McCallum said in his research report, 'without access to information, it is near impossible for persons with disabilities to formulate workable opinions'.¹⁹

Under article 21, States Parties must put in place appropriate measures to ensure people with disability can exercise their right to freedom of expression and opinion. These include the freedom to seek, receive and impart information and ideas on an equal basis with others. For example:

- Information that is intended for the general public must be provided to people with disability in accessible formats and technologies appropriate to different kinds of disabilities in a timely manner and without additional cost.²⁰
- In official interactions, States Parties must accept and facilitate the use of sign languages, braille, augmentative and alternative communication, and all other accessible means, modes and formats of communication that people with disability may choose.²¹

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- States Parties must urge private entities that provide services to the general public, including through the internet, to provide information and services in accessible and usable formats for people with disability.²²
 - States Parties must encourage the mass media, including those who provide information through the internet, to make their services accessible to people with disability.²³
 - States Parties must recognise and promote the use of sign languages.²⁴

Accessible information and communications are also critical in emergency situations and natural disasters. Under article 11, States Parties must undertake ‘all necessary measures to ensure the protection and safety of persons with disabilities in situations of risk, including situations of armed conflict, humanitarian emergencies and the occurrence of natural disasters’. Articles 11 and 21 when read together require States Parties to ensure emergency information is made available in accessible formats such as sign language and Easy Read formats.²⁵

The CRPD Committee stated in *General comment no. 2*:

In situations of risk, natural disasters and armed conflict, the emergency services must be accessible to persons with disabilities, or their lives cannot be saved or their well-being protected (art. 11). Accessibility must be incorporated as a priority in post-disaster reconstruction efforts. Therefore, disaster risk reduction must be accessible and disability-inclusive.²⁶

Australia’s compliance with the *CRPD*

In 2019, the CRPD Committee expressed its concerns about Australia’s progress in meeting its obligations under articles 9 and 21. It said Australia has lacked comprehensive and effective measures to meet all its accessibility obligations under the *CRPD*. This includes a lack of information and communications technologies and systems (relevant to article 9).²⁷ It also said that, aside from a provision under the *Disability Discrimination Act 1992* (Cth) (*DDA*), there are no legally binding information and communications standards requiring information to be fully accessible to people with disability.²⁸

The CRPD Committee’s views reflected concerns raised in the Australian Civil Society Shadow Report lodged with the CRPD Committee. The shadow report argued ‘there are no information and communications standards that require information to be fully accessible’. Accordingly, ‘there are no mandated minimum standards for government and public sector organisations to ensure web accessibility and usability, and for accessible information and services to be provided to the public’.²⁹ The shadow report quoted an online survey of more than 1,000 people, which found that 67 per cent of people with disability describe government information as inaccessible or difficult to understand.³⁰

The shadow report also argued that many people with disability cannot enjoy freedom of expression and opinion because they do not have communication supports, or equitable access to information.³¹

The Australian Human Rights Commission's (AHRC) submission to the CRPD Committee argued people with disability cannot access information and methods of communication on an equal basis.³² The AHRC recommended the Australian Government:³³

- undertake a gap analysis of Australia's laws and policies to identify the measures it can take to ensure accessibility on an equal basis, including accessibility of information and methods of communication
- increase captioning targets
- mandate that 10 per cent of television programs be audio-described
- cooperate with the states and territories to ensure that all information about changes in laws and policies be made fully accessible
- ensure the 'Australia.gov.au' website complies with web content accessibility guidelines.

In his report, Professor McCallum suggested the CRPD Committee's concluding observations 'broadly' agreed with the AHRC and the shadow report, particularly on article 9:³⁴

it is clear that the Australian Government has taken meaningful steps to comply with article 9, but more work is needed to ensure full accessibility in public and private spaces across Australian society.³⁵

Professor McCallum said in relation to article 21, 'it is clear that since Australia ratified the *CRPD* in mid-2008, the Government has made efforts to make information more accessible to persons with disabilities'.³⁶

Nonetheless, the CRPD Committee recommended the Australian Government:

- take necessary legislative and policy measures, such as the development of public procurement criteria, to implement the full range of accessibility obligations under the *CRPD*, including those on information and communications technologies and systems, and ensure there are effective sanctions for non-compliance (relevant to article 9)³⁷
- develop a plain language law requiring government agencies to use clear communication (relevant to article 21)³⁸
- develop legally binding information and communications standards so that information, especially information about significant changes to laws, policies, systems and obligations, is provided in accessible modes, means and formats, including braille, Easy Read and sign language (Auslan), and that communication supports are routinely available (relevant to article 21)³⁹
- promote and support the use of sign language (Auslan) and take steps to ensure that qualified sign language interpreters are available (relevant to article 21).⁴⁰

To date, the Australian Government has not adopted these recommendations.

The CRPD Committee may consider individual complaints alleging contraventions of the *CRPD*, when all Australian remedies have been exhausted. In 2022, the CRPD Committee considered a complaint brought by Ms Lauren Henley about a lack of audio described television content for people who are blind or have low vision.⁴¹ She argued the Australian Government provided limited funding for audio described television content (14 hours a week of audio described content on the two public broadcasters, SBS and the ABC).⁴² The CRPD Committee concluded that Australia failed to fulfil its obligations under articles 9(1)(b) and 30(1)(b), read in conjunction with articles 4(1) and (2) of the *CRPD*.⁴³

In response to Ms Henley's complaint, the CRPD Committee made several recommendations for Australia's consideration, including that it:

adopt action plans and strategies to identify existing barriers to accessibility, including the provision of audio description services to persons with visual impairments, set time frames with specific deadlines and provide both the human and material resources necessary to remove the barriers.⁴⁴

The CRPD Committee also recommended Australia 'take the necessary legislative and policy measures with a view to ensuring the provision of audio-description services to persons with visual impairment'.⁴⁵

On 11 April 2023, the Australian Government published its response to the CRPD Committee's findings and recommendations.⁴⁶ It recognised the importance of providing 'appropriate communications technology, such as audio description, to the full and equal enjoyment of human rights by persons with disabilities'.⁴⁷ It also committed to 'increasing connectivity, bridging the digital divide and improving access to communications for persons with disabilities'.⁴⁸

The Australian Government's response referred to the ADS. It said the Minister for Communications will develop an Associated Plan under the ADS that will be 'the vehicle for addressing access to communications technologies'.⁴⁹ The Associated Plan will also include 'steps to expand the availability of audio description in Australia'.⁵⁰

The Australian Government also provided the CRPD Committee with an overview of recent initiatives to support and increase the provision of audio description on free-to-air television.⁵¹ We discuss this initiative below under 'Government commitments to improve accessible information'.

The Australian Government disagreed with the CRPD Committee's finding that it contravened article 9, stating the measures it had taken were 'the most appropriate means by which to progressively realise the relevant Convention rights'.⁵²

Australia's legal obligations

Disability Discrimination Act 1992 (Cth)

In its 2018 periodic report to the CRPD Committee, the Australian Government stated, 'all Australian Government agencies are required to ensure that information and services are provided in a non-discriminatory and accessible manner' under the *DDA*.⁵³ However, the *DDA* prohibits discrimination against individuals in particular contexts, rather than imposing universal obligations to ensure accessibility, including in relation to information and communication.

As we discuss in detail in Volume 4, the *DDA* makes it unlawful to discriminate against a person with disability in the areas of work,⁵⁴ education,⁵⁵ access to premises,⁵⁶ provision of goods, services and access to facilities,⁵⁷ provision of accommodation,⁵⁸ land,⁵⁹ membership of clubs and unincorporated associations,⁶⁰ participation in sport,⁶¹ and the administration of Commonwealth laws and programs.⁶² These are all areas where information and communications issues arise for people with disability.

For the purpose of the *DDA*, discrimination occurs if:

- a person with disability is treated less favourably compared to a person without the disability in similar circumstances, and a reason for the treatment is the person's disability (**direct discrimination**)⁶³
- there is a failure to make reasonable adjustments for the person with disability, which has the effect that the person with disability is treated less favourably compared to a person without the disability in similar circumstances (**direct discrimination and adjustments**).⁶⁴ A reasonable adjustment is an alteration or modification made by a person for the person with disability,⁶⁵ unless making the adjustment would impose an unjustifiable hardship on the person⁶⁶
- a person with disability does not or cannot comply with a requirement or condition imposed on them because of their disability, and the requirement or condition disadvantages or is likely to disadvantage people with the same disability (**indirect discrimination**)⁶⁷
- a condition or requirement is imposed and there is a failure to make reasonable adjustments for the person with disability that would enable the person to comply with the requirement or condition, and the failure disadvantages people with disability (**indirect discrimination and adjustments**).⁶⁸

Disability discrimination may occur in cases where a person with disability needs interpreters or readers that are not provided.⁶⁹

A person who alleges discrimination may make a complaint to the AHRC. The AHRC may investigate and conciliate a complaint. If the complaint cannot be resolved by conciliation, a person may commence a legal proceeding in the Federal Court or Federal Circuit and Family Court of Australia to have the complaint determined and secure remedies for a breach of the *DDA*. We examine this process in more detail in Volume 4.

There have been a number of successful complaints concerning discrimination and accessible information or communication. For example:⁷⁰

- *Scott and Disabled Peoples International (Aust) Ltd v Telstra Corporation Ltd*⁷¹ resulted in a finding that Telstra's failure to provide services that were accessible to customers who were Deaf or had 'profound hearing loss' was indirect discrimination in the provision of services, in breach of section 24 of the *DDA*.⁷²
- *Maguire v Sydney Organising Committee for the Olympic Games (SOCOG)*⁷³ resulted in a finding that SOCOG breached section 24 of the *DDA* by failing to make its website accessible for blind and vision impaired people who wanted to purchase tickets for the 2000 Sydney Olympic Games.⁷⁴
- *Catholic Education Office v Clarke*⁷⁵ resulted in a finding that a school discriminated against a deaf student by developing a model of support that did not consider reasonable alternatives for the provision of Auslan interpreters as requested by the student and his family.⁷⁶
- *Hurst v Queensland*⁷⁷ resulted in a finding that a school discriminated against a deaf student by requiring her to be taught in signed English without the assistance of an Auslan interpreter, as she was 'not able to comply' with the condition because she would suffer serious disadvantage.⁷⁸
- *Innes v Rail Corporation of NSW (No 2)*⁷⁹ resulted in a finding that RailCorp discriminated against people with a sight impairment by failing to ensure there were clear and audible announcements on New South Wales trains.⁸⁰
- *Hinton v Alpha Westmead Private Hospital*⁸¹ resulted in the Full Court of the Federal Court finding it was plainly arguable that refusing to provide Auslan services to the Deaf husband of a wife who wished to confer with him during medical treatment could amount to discrimination of an associate under section 7 of the *DDA* in the provision of services.⁸²
- *Ryan as Personal Representatives of Estate of Late Peter John Ryan v Sunshine Coast Hospital and Health Service*⁸³ resulted in a finding that a hospital had discriminated against an applicant who lived with a degenerative sight condition and relied on braille, tactile signage and tactile ground surface indicators. The design and construction of the hospital inhibited the ability of a person with vision impairment to navigate both the interior and exterior of the building.⁸⁴

The *DDA* also authorises the Attorney-General to make disability standards for areas in which disability discrimination is unlawful.⁸⁵ Three sets of disability standards have been made to date. These include the *Disability Standards for Accessible Public Transport 2002* (Cth) (Transport Standards), *Disability Standards for Education 2005* (Cth) (Education Standards) and *Disability (Access to Premises – Buildings) Standards 2010* (Cth) (Premises Standards).

Some standards deal with information and communication specifically. The Premises Standards require communications systems that are suitable for 'occupants who are deaf or hearing impaired'.⁸⁶ This is similar to the requirement in the Transport Standards for public address

systems in both premises and conveyances to provide a ‘message equivalent to the message received by people without a hearing impairment’ for the benefit of people who are deaf or hard of hearing.⁸⁷

The Transport Standards require that ‘general information about transport services must be accessible to all passengers’ and ‘all passengers must be given the same level of access to information on their whereabouts’ while on public transport.⁸⁸

We discuss the *DDA* and the disability standards further in Volume 4.

Other Australian laws

In 2018, the Australian Government informed the CRPD Committee of other mechanisms, apart from the *DDA*, that promote accessible communication in Australia.⁸⁹ For example:

- The *Broadcasting Services Act 1992* (Cth) imposes a captioning regime for programs broadcast on free-to-air and subscription television in Australia. Subscription television licensees must also meet captioning targets that will gradually increase until they reach 100 per cent of programming by 1 July 2033.⁹⁰ The *Broadcasting Services Act 1992* (Cth) is monitored and regulated by the Australian Communications and Media Authority.⁹¹
- The *Copyright Amendment (Disability Access and Other Measures) Act 2017* (Cth) contains provisions enabling people who would otherwise have difficulty reading, viewing, hearing or comprehending copyright material because of a disability to gain easier access to that material in educational institutions and not-for-profit organisations assisting persons with disabilities.⁹²

State and territory legislation

All states and territories have enacted laws making it unlawful to discriminate on the ground of disability.⁹³

Some state and territory legislation recognises accessibility of information as a principle.⁹⁴ Legislation in New South Wales, Victoria and South Australia:

- mandates the development of state disability plans, which set out government action towards disability inclusion across the state⁹⁵
- requires public authorities to create disability action plans, which set out measures to ensure their services are accessible to people with disability.⁹⁶

Western Australian legislation only requires public authorities to create ‘disability access and inclusion plans’.⁹⁷ Similarly, Queensland legislation requires government departments to develop ‘disability services plans’.⁹⁸ No state or territory has introduced mandatory standards requiring government agencies, businesses and other entities engaging with the public to provide information and conduct communications in a manner accessible to people with disability.

A general principle in the *Disability Inclusion Act 2014* (NSW) is that ‘people with disability have the right to access information in a way that is appropriate for their disability and cultural background, and enables them to make informed choices’.⁹⁹ All public authorities (including state government agencies and local councils) must prepare a disability inclusion action plan. The plan must show how the public authority will take into account the Act’s general principles, and must contain strategies for providing access to information for people with disability.¹⁰⁰

One principle in the *Disability Inclusion Act 2018* (SA) is that ‘people with disability have the right to access information in a way that is appropriate for their disability and cultural background, to enable them to make informed choices’.¹⁰¹ All South Australian authorities must prepare a disability access and inclusion plan, which must include strategies to support access for people with disability to information and communications.¹⁰²

The *Disability Act 2006* (Vic) provides that the purpose of the State Disability Plan is to further the objectives and principles under the Act.¹⁰³ One principle is that ‘persons with disability have the same right as other members of the community to access information and communicate in a manner appropriate to their communication and cultural needs’.¹⁰⁴ The exposure draft of the Victorian Disability Inclusion Bill (not yet introduced into Parliament) provides that the Minister may issue guidelines on accessible communication and information.¹⁰⁵

Access to information and communications in Victoria is protected under section 15(2) of the *Charter of Human Rights and Responsibilities Act 2006* (Vic).¹⁰⁶ However, the Charter does not contain provisions specifically addressing the rights of people with disability.

Similar provisions are included in the Australian Capital Territory’s *Human Rights Act 2004* (ACT)¹⁰⁷ and Queensland’s *Human Rights Act 2019* (Qld).¹⁰⁸ However those jurisdictions have no specific legislative provisions conferring the right to accessible information and communications on people with disability.

1.3. Experiencing inaccessible communication and information

Despite obligations under international and domestic law, many people with disability in Australia still cannot access information and communications on an equal basis with others. Throughout our inquiry, we have learnt that a failure to provide information in accessible formats and to facilitate appropriate communication with people with disability can have serious consequences. This can lead to poor health, education and justice outcomes,¹⁰⁹ reduce employment opportunities¹¹⁰ and increase the risk of harm during emergencies.¹¹¹ People with disability who experience communication barriers and have high support needs are at increased risk of violence, abuse, neglect and exploitation.¹¹²

COVID-19 and other emergencies

Many people with disabilities feel as if they have been overlooked. Lack of information available to people with disabilities has meant that they are often the last to be educated about the risks associated with the state of emergency.¹¹³

Accessible information and communications are essential to ensuring good health, safety, wellbeing and the preservation of life of people with disability. This is particularly evident during emergency situations and natural disasters. A lack of accessible information and communications during emergencies puts people with disability at risk of deteriorating mental health, injury and death.¹¹⁴

We conducted two public hearings and published two issues papers that considered the experiences of people with disability during the COVID-19 pandemic and natural disasters.¹¹⁵ We heard evidence exposing the absence of accessible information and communications:

- during the early stages of the pandemic,¹¹⁶ but continuing throughout the various waves¹¹⁷
- explaining the COVID-19 vaccine roll out¹¹⁸
- during other emergencies and natural disasters including major bushfires and floods.¹¹⁹

At Public hearing 5, 'Experiences of people with disability during the ongoing COVID-19 pandemic', Dr Meltzer said:

accessible information is of critical importance to people with disability if they are to protect themselves from COVID-19. Having access to good quality, up-to-date information in accessible formats may quite literally be a matter of life and death.¹²⁰

Witnesses at Public hearing 5 told us there was a lack of clear, consistent and accessible information about COVID-19 and the measures taken to control it, particularly during the early stages of the pandemic. Speaking in a personal capacity, Ms Rosemary Kayess, the Vice Chairperson of the CRPD Committee, said she examined some of the Australian Government's major policy announcements in responding to COVID-19.¹²¹ Ms Kayess identified a two-month period, from mid-February to mid-April 2020, where 'there was no active or coordinated plan for people with disability in the response to the COVID-19 pandemic'.¹²² During this time, 'people with disability had little or no targeted accessible information about the virus symptoms, and how to protect themselves'.¹²³ The absence of information for people with disability dating from the early days of Australia's COVID-19 response 'created significant fear, anxiety and confusion' among people with disability.¹²⁴

Dr Meltzer also examined information during the early stages of the pandemic. She compiled a list of accessible information that was disseminated between mid-March and late-May 2020.¹²⁵ Dr Meltzer acknowledged there were limitations to the approach she used to compile the list of accessible resources.¹²⁶ However, her work demonstrated:

- reliance on specialist information access services or disability advocacy groups to provide accessible information on COVID-19. These organisations have expertise and the trust of people with disability. However, leaving the production of accessible information to them ‘at a time of such critical public health messaging could be seen as an abdication of responsibility’ on the part of other relevant information outlets including news services and governments.¹²⁷
- a lack of timeliness in the production of accessible information. The Australian Government was criticised for its lack of a timely public health campaign on COVID-19 in general. However, more official information was available earlier in standard information formats for the general population¹²⁸ than in accessible formats for people with disability. During COVID-19 the situation was changing rapidly and this meant significant amounts of new and changed information were available in the mainstream media, but ‘only some of the groups who produced accessible information on COVID-19 were continually updating their offerings’ during the observed period.¹²⁹
- a limited range of formats. Most of the information was in Easy Read or Easy English format. The next most common format was Auslan. Other formats – such as ‘social stories’, entirely pictorial (wordless) information and images for users of alternative and augmentative communication systems – were available only rarely, and not necessarily from Australian-based organisations.¹³⁰

Overall, Dr Meltzer observed:

With the exception of Auslan translations on some key news broadcasts and some closed captioning, there is little other accessible information from mainstream news organisations. There is some very useful government department-branded accessible information on COVID-19, but ... it came out late and also did not cover all the same topics as other providers’ information.¹³¹

Responses to the *Emergency planning and response issues paper* expressed similar concerns about the lack of accessible information, and the quality and timeliness of information available during the early stages of the pandemic.¹³²

The Commissioners’ *Report of Public hearing 5* found the Australian Government had failed to consult people with disability and develop a specific plan addressing the needs of, and challenges faced by, people with disability. As a result, there was a lack of clear, consistent and accessible information about the pandemic and the measures taken to control it.¹³³ This had serious adverse consequences, including significant distress among people with cognitive disability.

The lack of accessible information and communications continued to be an issue after the early stages of the pandemic. The evidence at Public hearing 12, 'The experiences of people with disability in the context of the Australian Government's approach to the COVID-19 vaccine rollout', revealed that a core problem with the vaccine rollout was the failure to provide information in accessible formats to people with disability. As a result, many people with disability lost trust in the Australian Government's handling of the early stages of the COVID-19 vaccine rollout. Uncertainty and confusion were generated among people in the disability community.

Ms Tara Elliffe and the CEO of Inclusion Australia, Ms Catherine McAlpine, told us the Australian Government's Easy Read materials on COVID-19 and vaccinations were not user friendly, and people with intellectual disability were not able to understand them.¹³⁴ Ms Elliffe and Ms McAlpine demonstrated how there was too much unnecessary information, the material was too complex, and the online navigation required to access the information was too complicated.¹³⁵ Ms McAlpine said that, while there are 'formal' or technical criteria for the preparation of Easy Read materials, conformity with those rules alone does not make information accessible.¹³⁶

The Commissioners' *Report of Public hearing 12* emphasised the importance of consultation with people with disability and disability representative organisations in designing programs for people with disability, including people with intellectual disability. Had people with intellectual disability been consulted when the Easy Read material about COVID-19 and the vaccination program was being prepared, the information would have been more effective.¹³⁷

The Commissioners' *Report of Public hearing 12* also found the Australian Government Department of Health did not provide information in a form that ensured, as far as practicable, it would reach and be understood by people with disability, especially people in disability residential settings and people with intellectual disability. The absence of clarity in the flow of information contributed to confusion among people with disability.¹³⁸ This applied to information about the rollout of vaccines to people with disability. The communications deficiencies damaged the Australian Government's perceived credibility and trustworthiness among many people with disability.¹³⁹

We recommended the Australian Government prioritise clear and accessible communications for people with disability and the disability sector generally on the vaccine rollout and the importance of vaccination for people with disability.¹⁴⁰ The Australian Government noted this recommendation, and accepted all other recommendations arising from the hearing.¹⁴¹

The *Emergency planning and response issues paper* recorded that during the 2019–2020 bushfires people with disability were at risk because of inadequate or inaccessible communication and information broadcasts. For example, there were insufficient Auslan interpreters available and little information in Easy English.¹⁴² Scope (Australia) Ltd stated in its response that 'there was inadequate accessible communication available about the bushfires, particularly in formats suitable for people with low literacy levels and users of Augmentative and Alternative Communication'.¹⁴³

The Royal Commission into National Natural Disaster Arrangements heard the Emergency Alert System is considered 'outdated' and undergoing review to adopt the best technology and better

account for people with disability.¹⁴⁴ The Royal Commission considered ‘some groups require special consideration and arrangements to evacuate’ which included people with disability.¹⁴⁵

We received evidence and information about issues of particular concern to specific groups of people with disability during public emergencies. At Public hearing 5, the late Ms Leonie Jackson, Executive Manager, Advocacy and Strategic Partnerships of The Deaf Society and Deaf Services Ltd (now Deaf Connect), said Deaf people were at risk during the pandemic because they had limited access to information. She said that most people get their information from radio, television and the internet. However, these platforms are not accessible to many members of the Deaf community.¹⁴⁶ First Nations Deaf people are at increased risk because the sign language that interpreters use on television broadcasts (Auslan) is different from First Nations sign language systems.¹⁴⁷

In response to the *Emergency planning and response issues paper*, the Deaf Society and Deaf Services Ltd (now Deaf Connect), Deafness Forum Australia, and the Deafness Council of Western Australia emphasised that, during emergencies, governments and media must recognise the diverse needs of people who are d/Deaf, are hard of hearing, are hearing impaired, have a hearing loss or are d/Deafblind.¹⁴⁸ There is no ‘one size fits all’ for this group. Some people prefer to access information and communications in written English, including through the use of captions. Others rely on Auslan interpreters.¹⁴⁹ Members of the d/Deafblind community may communicate through ‘tactile forms of English and/or Auslan such as tactile fingerspelling, hand-over-hand signing and visual frame signing.’¹⁵⁰ We examine the diverse communication needs of the d/Deafblind community later in this chapter.

Vision Australia submitted there has been ‘significant progress’, but information was still relatively inaccessible for people who are blind or have low vision:

A vast amount of information regarding COVID-19 in relation to hand hygiene, social distancing practices, various movement restrictions/lockdowns and the state of the pandemic in Australia was released in the form of graphs, charts and pictures/graphics without descriptions. For people who are blind or have low vision, all of these formats are essentially impossible to access.¹⁵¹

Vision Australia submitted that, for older people who are blind or have low vision, there is even less information because they are less likely to have the skills to access information in alternative formats (for example, online or on a smartphone).¹⁵²

Down Syndrome Australia described the difficulty of accessing information during COVID-19 as a ‘critical’ issue for its members.¹⁵³ Family members were concerned about the lack of information provided in plain language and Easy Read formats.¹⁵⁴

The specific needs of First Nations people and children with disability were also identified. The First Peoples Disability Network said that during the pandemic, culturally appropriate and accessible information for First Nations people with disability was scarce.¹⁵⁵ Children and Young People with Disability Australia told us how a lack of targeted information for children and young people with disabilities and their families during the pandemic exacerbated ‘distress and uncertainty’.¹⁵⁶

Responses to the *Emergency planning and response issues paper* also highlighted the specific risks that people with disability face given they may rely on others for information or have poor access to the internet or digital technologies. The Northern Territory Office of the Public Guardian told us that internet access in remote and very remote communities is ‘poor and very limited’. This ‘significantly affected the distribution of information in language’ for First Nations people during the pandemic.¹⁵⁷ The Centre of Research Excellence in Disability and Health and Dr Claire Spivakovsky told us people with disability who live in congregated settings may not be able to access information during emergency situations.¹⁵⁸

The totality of the evidence and information we have received shows there is a need for better forward planning about information and communications strategies during situations of disaster or emergency. This planning needs to involve consultation and, where appropriate, co-design with people with disability and their representative organisations.

The COVID-19 pandemic revealed the deficiencies in the accessibility of information and communications for people with disability generally. Ensuring accessible information and communications in times of emergency, such as a pandemic or natural disaster, is critical in preparing for future emergencies.

Health care

Do Easy Read. I want for people to try and show in different ways by using pictures and words together. Speak to the person when they have a support person with them. Don't speak to the support person, speak to the person with disability. People like using big words. I don't like big words.¹⁵⁹

Even outside exceptional circumstances like a pandemic, people with disability should have regular access to information concerning their health. At Public hearing 4, ‘Health care and services for people with cognitive disability’, we heard about the communication barriers that people with cognitive disability often face when they interact with health professionals. For example, health professionals may not have the knowledge, skills and attitudes needed to communicate effectively with people with disability. There may be system-level barriers to the provision of appropriate communication adaptations and supports.

We also heard how accessible health information and communications contribute to realising the right to health for people with disability.

Accessible information and communications are important for health literacy and self-advocacy. Professor Julian Trollor, for example, explained that health information in formats accessible to people with cognitive disability is important because it assists them to understand and manage their own health needs. However, this type of information is not routinely available.¹⁶⁰

People with disability also use accessible resources to assist them to communicate in clinical interactions. Ms Tara Elliffe and Mr Robert Strike AM said the use of pictures and Easy Read documents helps them understand what is happening.¹⁶¹ Ms Jayne Lehmann, the mother of Sarah, who lived with intellectual disability, gave evidence at Public hearing 4. She said providing 'low literacy pictures or information with symbols in addition to easy-read would help to de-escalate anxiety levels and prevent the behaviours that can be triggered' when people with intellectual disability and health professionals interact in hospitals.¹⁶²

Accessible health information and communications about strategic and operational policy are important to enable people with disability to participate in the design, delivery, implementation and evaluation of health services and treatment. In Public hearing 4 we heard that in New South Wales people with intellectual disability and their families, carers or staff can access a range of health consumer material in Easy Read, infographics or videos, but there were no NSW Health policies in Easy Read format.¹⁶³

It is also important to provide information in accessible form to ensure public health campaigns, for example, about healthy lifestyles and preventive care, reach people with disability. A lack of access to preventive health care is a key reason for the health disparities faced by people with disability, as we heard in Public hearing 4 and discuss in Chapter 4, 'Health care and treatment'.¹⁶⁴

In December 2022, NSW Health advised us that it has drafted a policy on accessible communications. The policy sets out the principal steps and key considerations for developing accessible communication materials. NSW Health is also producing guidelines, templates, training modules and other support tools to complement the policy.¹⁶⁵ In addition, Easy Read 'explanations' of different policies are being drafted.¹⁶⁶

Similar health consumer material is available in other states and territories including Victoria,¹⁶⁷ South Australia,¹⁶⁸ Tasmania,¹⁶⁹ Western Australia¹⁷⁰ and Queensland.¹⁷¹ The Council for Intellectual Disability has also published a range of health-related guides and factsheets in accessible formats.¹⁷²

However, the extent of health information provided in accessible formats varies significantly between jurisdictions, as do the formats themselves. The result is unequal access to information for people with disability across Australia.

We make recommendations in Chapter 4 addressing the need for adaptations in clinical settings for people with disability. These recommendations include disseminating information about the adaptations available in a range of accessible formats.

Disability service provision

People with disability need to be able to communicate effectively with disability service providers so they can exercise choice and control over the services they are receiving. It is crucial that disability service providers understand how the person receiving support communicates and can use that mode of communication effectively.¹⁷³

When support staff do not understand how a person communicates, and when they do not often use communication plans and other communication methods, people with disability can find it difficult to tell staff about emerging concerns, for example changes in their health. Support staff should know the person well enough to be able to identify when their health or behaviour changes in ways that may indicate potential illness and the need for medical assistance.¹⁷⁴

Disability service providers must support staff to develop the skills they need to communicate with people according to their individual needs.¹⁷⁵ This is particularly important for people who do not communicate verbally.¹⁷⁶ Disability service providers should prioritise up to date communication plans when supporting people with disability.¹⁷⁷ A report that examined this issue in detail found over a third of those who required a communication plan did not have one in place.¹⁷⁸

In some cases, when people with disability do not have access to adequate communication support, their communication skills have regressed and behaviours of concern increased.¹⁷⁹ People who are non-verbal and do not have appropriate communication support may have their communication identified as behaviours of concern.¹⁸⁰

Respondents to the *Group homes issues paper* told us that those most at risk of abuse and neglect in group homes are people who are non-verbal and people who need a high level of support.¹⁸¹ The NDIS Quality and Safeguards Commission's Own Motion inquiry into supported accommodation reiterated the importance of effective communication between people with disability, their service providers, family members and other supporters. People with disability rely on these supports to make community connections, engage with informal supports and participate in a range of activities.¹⁸²

Education and employment

I was in tears. I was confused. The whole process was being focused on signing it, and despite not understanding it, I felt forced to sign it and that was because I didn't want to lose my job.¹⁸³

The educational and employment outcomes for a person with disability are influenced by the extent to which information and communications are accessible.

Evidence presented at Public hearing 24, 'The experience of children and young people with disability in different education settings', suggested students with disability were required to adapt to the pace at which communication in schools happen, rather than schools adapting to the particular communication requirements of students.¹⁸⁴ An inability to communicate with teachers, aides and peers can lead to isolation.¹⁸⁵ Similar evidence was presented at Public hearing 29.¹⁸⁶ These issues are further explored in Volume 7, *Inclusive education, employment and housing*.

When information and communications are inaccessible, people with disability can be prevented from securing and maintaining employment. At Public hearing 9, 'Pathways and barriers to open employment for people with disability', we heard about a number of physical and environmental barriers preventing people with disability from obtaining and maintaining open employment.

These include:

- inaccessible job advertisements, which are not available in Easy Read format or accessible by screen readers. This means people with disability are excluded from applying for a job¹⁸⁷
- workplace environments that do not provide or support accessible means of communication and that use technology, design and websites that are inaccessible to employees with disability.¹⁸⁸

Inaccessible technology can include:¹⁸⁹

- computer systems or programs that cannot run screen readers or speech-to-text
- touch screens without audio descriptors
- training videos without Auslan translation or captions.

A requirement for all employees to use the telephone to communicate will disadvantage some employees with disability.

The barriers that prevent people with disability from obtaining and maintaining employment are further examined in Volume 7.

The provision of inaccessible information and communications in the workplace was also examined at Public hearing 22, 'The experiences of people with disability working in Australian Disability Enterprises' (ADEs). A number of witnesses spoke about poor communication and a lack of accessible information in ADEs.¹⁹⁰

'Gert' said:

ADE staff would put notices up around the workplace and expect the supported employees to read them and take the information home to their parents and support people ...The staff at that ADE knew ... supported employees could not read.¹⁹¹

Ms McAlpine said the lack of information in accessible formats in ADEs continues to be an ongoing problem.¹⁹² Some information is not provided in Easy Read. Even when it is, there is a lack of acknowledgement that Easy Read materials are meant to be read with support.¹⁹³

'Tay' has a learning disability. Tay told us they 'learn best by doing things repetitively, writing things down, and having things explained to me'.¹⁹⁴ In 2020, Tay was told they needed to sign a new service agreement by a certain date or they would lose their job.¹⁹⁵ Tay was not given support to understand the agreement, and did not understand the additional materials accompanying the agreement:

I was in tears. I was confused. The whole process was being focused on signing it, and despite not understanding it, I felt forced to sign it and that was because I didn't want to lose my job.¹⁹⁶

Tay and 'Marc' told us that ADEs need to provide employees, and their families and supporters, with clear, consistent, transparent and timely information.¹⁹⁷ Marc has an intellectual disability. He has worked in an ADE for over 30 years. He said it is important employees understand what is happening at the workplace.¹⁹⁸

In its response to the submissions of Counsel Assisting in Public hearing 22, ADE Bedford Group said:

undoubtedly Marc and Tay's evidence is valuable in terms of exploring the impressions of some individual employees in ADEs, however it ought not be elevated to evidence capable of supporting findings about the experience more broadly of people in, or the operation of, the ADE sector.¹⁹⁹

Clear, timely communication is an essential feature in safeguarding against violence, abuse, neglect and exploitation in the workplace.²⁰⁰ Inaccessible information and communications can result in a person with disability not being fully aware of their rights at work.²⁰¹ The *Supported Employment Services Award* provides at clause 31, 'Rights at Work for Supported Employees':

When dealing with employment matters affecting supported employees, the employer shall take all reasonable steps to provide such employees with the information they require to exercise their employment rights.²⁰²

In its 2019 review the Fair Work Commission said that the *Supported Employment Services Award 2010* was varied to insert this clause because:

The evidence makes clear that disabled employees working in ADEs are a vulnerable group, and are likely to require information, representation, consultation and assistance concerning workplace decisions which affect their interests to an extent that is far greater than for non-disabled employees.²⁰³

The clause came into effect on 1 March 2010. However, Ms McAlpine said she was not aware if this change had made any difference to the people Inclusion Australia represents.²⁰⁴

At Public hearing 22 we also heard Services Australia provides limited accessible information.²⁰⁵ In response, the Australian Government said the 'Services Australia website applies plain English principles supporting people with low literacy levels and those experiencing vulnerability and includes "listen" and print options and other tools'.²⁰⁶ The Australian Government did not refer to information in Easy Read or in Auslan interpretation in Services Australia offices. The response reflects the limited range of formats in which digital information is currently provided, and is consistent with evidence from lived experience witnesses and their advocates.

Sexuality and relationships

... when the assault occurred I thought, 'Where can I go? Who can I tell?' My parents live very far away from me. I use Auslan to communicate. And at the time, I also didn't have the words or the language to describe what occurred and who I was as a person.²⁰⁷

At Public hearing 17, 'The experience of women and girls with disability with a particular focus on family, domestic and sexual violence', witnesses spoke about the need to ensure sex and relationship education is accessible.²⁰⁸ Research has also examined the lack of access to relationships and sex education provided to people with disability.²⁰⁹ Without access to this education, people with disability may be unable to recognise abuse, and perpetrators may be able to manipulate them into sexualised behaviours.²¹⁰

Ms Cathy Want is the Manager at Rosie's Place, a non-government organisation that primarily supports children and young people, especially people with intellectual disability, who have experienced sexual, domestic and family violence.²¹¹ Ms Want said that thought must be given to communication needs and how to present information in ways that are accessible – for example, resources in Easy Read format.²¹²

Ms Catherine Dunn shared her experiences as a Deaf woman.²¹³ She told us she received very limited sex education. The Auslan interpreter in her sex education class lacked the signs to translate the content adequately.²¹⁴ She explained that when she was assaulted, she 'didn't have the words or the language to describe what occurred', and this acted as a barrier to disclosing.²¹⁵

We analyse the need for equal access to consent, relationships and sexuality education for students with disability in Volume 7 and examine the impact when this is not available in Volume 10, *Disability services*.

Criminal justice system

I feel the court process should have more simple information and guides for people that have limited reading and writing ability, like pictures and just making it simple and easy – videos explaining the process.²¹⁶

We heard about the effects of inaccessible information and communications throughout the criminal justice system. In response to the *Criminal justice system issues paper*, Speech Pathology Australia told us people with speech, language and communication needs are more likely to experience negative consequences when engaging with the criminal justice system because the system is not able to provide alternatives to verbal communication.²¹⁷

It can impact on participation in investigative interviews, witness competency, fitness to plead / stand trial, relationships with legal counsel, understanding of legal concepts and constitutional rights, ability to discuss issues related to safety and risk, perception of reliability of the testimony, it also has implications on an individual's ability to participate in verbally-mediated interventions, and post release employment prospects.²¹⁸

In private sessions, people with disability also described some of the communication barriers they encountered when engaging with the police. A Deaf man told us about the communication barriers he encountered when he was interacting with the police and they had failed to arrange an Auslan interpreter.²¹⁹ In addition, a Deaf woman, who uses Auslan as her first language, told us that a police officer incorrectly provided her a phone number for the National Relay Service speech-to-speech service.²²⁰

We also received evidence about inaccessible information and communications in prison settings. In Public hearing 27, 'Conditions in detention in the criminal justice system', 'Alen', a Deaf person from New South Wales, told us that for the first four weeks of his imprisonment, he was unable to talk to anyone because he was not provided with an Auslan interpreter.²²¹ For the remainder of his sentence, Alen was only able to access an Auslan interpreter when he met with his Legal Aid solicitor.²²² He was unable to participate in prison activities and programs²²³ and communicate with others, including fellow prisoners and corrective service officers.²²⁴

Mostly I was bored because I had no one to talk to. I felt really lonely. I would let people know I was Deaf, and then after that I wouldn't speak to anyone.²²⁵

Mr Trevor Barker from Gallawah, who works in Victorian prisons, said that Deaf prisoners have to wait eight to 10 weeks to access an Auslan interpreter in prison.²²⁶

Culturally and linguistically diverse people with disability

People with disability use many languages

Australia is made up of people from more than 300 ancestries, 257 languages and 250 countries of birth.²²⁷ In light of this broad diversity, we examined data from the Australian Bureau of Statistics to identify the languages that people with disability speak. We took data from the *Survey of Disability, Ageing and Carers* from 2018 and the Census from 2021.²²⁸ Our analysis focussed on people aged under 65.

The analysis found that the top three language groups that people with disability aged 0 to 65 speak at home are Mandarin and Cantonese (Chinese), Middle Eastern Semitic (Arabic and Hebrew) and Indo-Aryan, including Hindi and Punjabi (Indian).²²⁹

Additional barriers to accessing information and communications

People with disability from culturally and linguistically diverse backgrounds experience unique and compounded barriers when seeking access to information and communications. We commissioned the University of New South Wales' Social Policy Research Centre and the National Ethnic Disability Alliance (NEDA) to produce a report, *Towards best-practice access to services for culturally and linguistically diverse people with a disability*, which explores some of these barriers.²³⁰

In a separate submission, Adult Multicultural Education Services Australia said people with disability from culturally and linguistically diverse communities may be unable to access information and communications due to:²³¹

- the information and communications being provided in inaccessible formats
- the absence of information translated into community languages
- a lack of culturally appropriate information
- the difficulties faced by members of culturally and linguistically diverse communities who have limited access to digital technologies.

The major reasons for the inaccessibility of information for people with disability from culturally and linguistically diverse backgrounds are limited access to qualified and skilled interpreters and insufficient material translated into community languages.²³²

Government agencies and services often require consumers to use English to communicate. Inaccessible information and communications may become a barrier to connecting and forming relationships with service providers.²³³ It is also a barrier to understanding a person's rights in respect of these systems or available complaint mechanisms.²³⁴ Inability to access information and communications in languages other than English can be particularly problematic when attempting to navigate different and complex systems, such as health, Centrelink, the NDIS, migration and visa requirements.

Witnesses at Public hearing 29 explained how language barriers affect a non-English speaking person's ability to fill out forms,²³⁵ and understand correspondence from a government agency or service.²³⁶ The National Disability Insurance Agency (NDIA), for example, acknowledged the NDIS relies predominantly on online forms.²³⁷ This means that, increasingly, people who engage with government agencies and services need a certain degree of digital literacy and access to technology. This adds further complexity for people who experience language barriers.

Witnesses emphasised the important role of community leaders in navigating systems and services.²³⁸ Dr Berhan Ahmed, CEO of Africause, said community leaders from culturally and linguistically diverse communities help bridge the gap between members of their communities and mainstream services.²³⁹ He said the information that community leaders provide is critical because there was often limited knowledge among community members about how to access services.²⁴⁰

Responses to the *Experiences of culturally and linguistically diverse people with disability issues paper* also discussed barriers to accessible information and communications. In a joint response, National Ethnic Disability Alliance (NEDA), People with Disability Australia and the Federation of Ethnic Communities Councils of Australia described barriers to engaging with Australian Government agencies, including language and cultural barriers and difficulty navigating complex systems and processes.²⁴¹

The joint response also noted that limited computer skills and digital literacy may exacerbate the lack of access to information.²⁴² Similarly, AMPARO Advocacy said more needs to be done to ensure people with disability from culturally and linguistically diverse backgrounds can access services and supports:

simply providing information about a service or a link to a website will not enable the person or their family to access the service. This may be due to low levels of literacy or English skills, a lack of confidence in their right to request assistance, or a lack of a culturally competent response from the service provider.²⁴³

First Nations people with disability

First Nations people with disability experience additional barriers to accessing information and communications. At Public hearing 25, 'The operation of the NDIS for First Nations people with disability in remote and very remote communities', First Nations witnesses described the language in NDIS plans as 'technical' and 'bureaucratic'. Some said their plans were not properly explained to them.²⁴⁴ Others had difficulty understanding the consequences of signing forms, such as an agreement to receive NDIS services. Even 'Plain English' versions can be hard to understand.²⁴⁵ An internal NDIA report on a trial undertaken in Ngukurr found the language used to communicate NDIA information is often 'not culturally appropriate which leads to misinformation, confusion and, potentially, mistrust'.²⁴⁶

Some witnesses at Public hearing 25 said they were confused about how much funding is in their plan and what the funding can be used for in accessing disability supports.²⁴⁷ This limits

their ability to exercise choice and control. One witness, Ms Emily Sherwood, said she would prefer to have someone sit down with her regularly and discuss what her funds are, how they are being spent and how she would like to spend her funds.²⁴⁸

We were told there is a lack of NDIS resources available in First Nations languages.²⁴⁹ The Ngaanyatjarra Pitjantjatjara Yankunytjatjara (NPY) Lands are located across Western Australia, South Australia and the Northern Territory. They are home to Anangu (First people).²⁵⁰ Mrs Kunmanara (Margaret) Smith and Ms Kim McRae from the NPY Women's Council told us that language barriers prevent First Nations people with disability from being able to understand their NDIS plans.²⁵¹ They also said that plans were in writing, and not everyone on the NPY Lands is literate, meaning they face an additional barrier.²⁵² They explained that, aside from language barriers, cultural differences mean that a lot of the concepts within NDIS plans are incomprehensible to Anangu.²⁵³

Ms Smith and Ms McRae told us:

Anangu typically speak English as a second, third or fourth language. Some of our clients have only a few words of English. Most people are not functionally literate, especially when faced with the bureaucratic concepts and the language used by mainstream services. Anangu do not access the internet for information, and neither do they look for written pamphlets. People's culture on the NPY Lands is an oral one, in which personal privacy is crucial. Anangu will rarely discuss personal issues with someone they do not know and trust.²⁵⁴

In addition, many responses to the *Experiences of First Nations people with disability in Australia issues paper* identified language barriers and an overreliance on written and electronic communication as particular issues for First Nations people with disability when attempting to access support.²⁵⁵

1.4. Improving accessibility of information and communications

Existing initiatives to promote accessible information and communications

Australia-wide initiatives

A number of initiatives at the national level promote accessible communication and information. For example, the National Relay Service allows people who are d/Deaf or hard of hearing to access standard telephone services.²⁵⁶ The Australian Government Print Disability Services Program provides funding for organisations to convert print material into alternative formats to meet the needs of people described as having 'print disability' (including people who are blind or have low vision, people with physical disability, and people with cognitive disability). In June 2020, the ABC commenced broadcasting audio-described content. With recent changes to funding, the amount of content which is audio described is increasing.²⁵⁷

The Australian Government *Style manual* states that ‘Government services and products need to be available to everyone. This means creating inclusive content’, including for people with disability. The *Style manual* provides guidance on creating accessible content.²⁵⁸ Some Australian Government procurement policies also contain accessibility requirements.²⁵⁹

In addition, the Australian Government Digital Transformation Agency’s Digital Service Standard provides guidance to Australian Government agencies to support them to meet the Web Content Accessibility Guidelines 2.0 Level AA standard.²⁶⁰

State and territory initiatives

State and territory governments have also introduced laws, policies and programs to support the provision of accessible information and communications, including online and within the health and justice systems.

Initiatives to promote accessible information and communications online include the *Digital Inclusion in WA Blueprint* in Western Australia²⁶¹ and the Accessibility, Affordability, Ability Digital Inclusion Project in Queensland.²⁶²

In health care, Queensland has developed *Julian’s Key Health Passport* – a patient/carer-controlled tool designed to improve communication and empower people with disability, their families and carers to be as actively involved in their healthcare and decisions as possible.²⁶³ Other public health initiatives include:

- Victorian Department of Health and Human Services’ Disability Liaison Officer program.²⁶⁴ Disability Liaison Officers are able to provide specialised information and support to people with disability and assist with coordination of health care
- New South Wales’ Health Policy Directive, ‘Interpreters – Standard Procedures for Working with Health Care Interpreters’, which ‘provides clear direction to health care staff and services about when and how to work with’ interpreters, including Auslan interpreters.²⁶⁵

A number of states have intermediary schemes to support people considered vulnerable, usually witnesses, in their interactions with police or courts. These schemes often include people with disability.²⁶⁶

A key role of the intermediary is to assist with overcoming communication barriers. For example, under the ACT Intermediary program, intermediaries are experienced with facilitating communication for witnesses with cognitive disability.²⁶⁷ One aim of Queensland’s plan to respond to domestic and family violence against people with disability is to ensure communication and support services and responses are trauma-informed and accessible.²⁶⁸ In New South Wales, the Locked Box allows young people to provide feedback and submit complaints anonymously about the safety and quality of care they receive in a Youth Justice Centre.²⁶⁹ Youth Justice NSW worked with the Centre for Intellectual Disability to ensure the resources and processes associated with this mechanism are ‘highly accessible and client-focused’.²⁷⁰

Organisational and agency-level initiatives

Some organisations have voluntarily taken the initiative to improve communication and access to information. Scope (Australia) Ltd, a not for profit disability provider based in Victoria, has established a Communication Access Accreditation and associated Symbol, which is awarded to organisations that meet minimum standards for communication access.²⁷¹ The standards include a range of criteria to do with staff skills (for example, recognising staff who are willing to use novel methods of communication), an environment that supports communication (for example, quiet spaces are made available), and the use of clear signage and accessible written information.²⁷² The Symbol has been endorsed by the International Society for Augmentative and Alternative Communication, the Victorian Department of Health and Human Services and National Disability Services.²⁷³

In response to the *Promoting Inclusion issues paper*, Scope said over 200 businesses and services across Victoria have been awarded the Communication Access Symbol.²⁷⁴ In Scope's view:

Adopting communication access standards across at [sic] all government, non-government institutions and the private sector is one practical way to promote inclusion through reducing the barriers associated with limited communication. These standards seek to enable everyone to get their message across and understand the information given to them.²⁷⁵

Some government agencies have internal policies and practices to ensure that accessible information and communications form part of their service delivery. At Public hearing 29, Ms Julie Inman Grant, eSafety Commissioner, told us the eSafety Commission's cyber abuse and complaints systems are fully accessible to people with disability. This is done by:²⁷⁶

- providing resources tailored to people with disability
- adhering to web accessibility guidelines and regular reviews (including reviews by an independent third party)
- using best-practice digital approaches such as plain language writing and search engine optimisation.

The eSafety Commission also works closely with accessibility inclusivity experts from organisations including the Centre for Inclusive Design, the Ethics Centre and the Australian National University College of Engineering and Computer Science.²⁷⁷

Commitments to improve accessibility of information and communications

Australia's Disability Strategy 2021–2031

Governments have made policy commitments on accessible communication and information. The ADS includes a policy priority focused on ensuring 'information and communication systems

are accessible, reliable and responsive'.²⁷⁸ There is no targeted action plan associated with this policy priority. However, governments have committed to providing more accessible information and communications through actions associated with other Targeted Action Plans.

For example, through the Emergency Management targeted action plan:

- the Australian Government has committed to work with state and territory governments to ensure that people with disability, their families and carers, their organisations and disability support service providers are given information on responding to health emergencies in accessible formats²⁷⁹
- Victoria has committed to funding two accessible emergency communications roles²⁸⁰
- Queensland has committed to considering approaches to emergency alert management systems and emergency information and warnings that are tailored to people with disability²⁸¹
- the Australian Capital Territory has stated it will continue to provide information in accessible formats for people with disability²⁸²
- the Northern Territory has committed to providing alternative accessible formats of information to support emergency management planning and risk assessments for people with disability, and taking measures to improve access to and the quality of Auslan in the Territory.²⁸³

Through the Community Attitudes Targeted Action Plan, Victoria committed to developing accessible information products for identified information needs.²⁸⁴ New South Wales has committed in its Safety Target Action Plan to developing and translating information resources about mental health services for people with intellectual disability.²⁸⁵ South Australia has stated it will 'investigate options' to develop Easy Read versions of key Housing SA information (for example, about tenancy agreements),²⁸⁶ provide accessible information on South Australia Police websites²⁸⁷ and create accessible information for women with disability about domestic, family and sexual violence.²⁸⁸ The ADS is discussed in detail in Volume 5, *Governing for inclusion*.

State and territory disability strategies and plans

State and territory disability strategies and inclusion plans include broad commitments to improving information accessibility. In some jurisdictions, efforts are being made to adopt a standardised approach to improving communication and information accessibility.

The NSW Disability Inclusion Plan 2021–2025 aims to ensure people with disability can have equal access to information. The plan states this will be implemented through the NSW Department of Customer Service working with all agencies to 'implement current international standards in digital accessibility ... to remove barriers that people may face accessing government services online'.²⁸⁹

In Victoria, one of the systemic reforms under the Inclusive Victoria: State Disability Plan (2022–2026) is ‘equitable access to key information in formats that are accessible’, recognising that this is ‘critical to ensuring the inclusion, participation and safety of people with disability’.²⁹⁰ The plan states it will ‘build capacity across government to provide inclusive, accessible and targeted communications for people with disability’, including by:²⁹¹

- ‘developing whole-of-government strategies and approaches to ensure we are meeting the communication needs of people with disability, through co-design with people with disability and building accessible communications awareness and expertise within the Victorian public service’
- ‘a particular focus in the first two years of the plan on improving accessible communications in emergency management and planning’.

In South Australia, ‘accessible and available information’ is a priority under Inclusive SA: State Disability Inclusion Plan 2019–2023. This priority will be supported by:²⁹²

- developing a toolkit to support state authorities to ensure communication about their services is available in a range of accessible formats. Formats may include Easy Read, Auslan, pictorial forms, large font, audible options, braille, closed captions and voiceover
- improving online accessibility of state government websites, including through implementation of the Online Accessibility Policy and related guidelines.

In the Northern Territory, the NT Disability Strategy 2022–2032 aims to ensure that ‘people with disability can access the places, information and services they need’. Improvement of ‘the accessibility of public information and communications’ is a corresponding priority.²⁹³ Relevant actions for 2022–2025 include:

- ensuring programs, services and communication involve inclusive practices where and when required²⁹⁴
- engaging the Aboriginal Interpreter Service and the Interpreter and Translating Service NT to increase the accessibility of information for people with disability²⁹⁵
- ensuring accessible information is provided for disaster and emergency management. This will be achieved by engaging interpreters and developing resources for people who do not speak English as their first language, and an Auslan interpreter²⁹⁶
- expanding ‘the use of technology’ to provide information about transportation in a variety of ways, including ‘large print, audio, different languages and Braille’ – for example, on ‘timetables on the website, at bus stops and interchanges’ – and improving the accessibility of the Bus Tracker App.²⁹⁷

In the Western Australian State Disability Strategy 2020–2030, ‘information’ is one of four strategic priorities under the ‘Rights and equity’ pillar.²⁹⁸ The strategy includes an outcome that ‘people with disability have access to the right information in the right ways so they can make informed choices and decisions’ as the corresponding outcome.²⁹⁹ The strategy states:

government agencies, community groups and other organisations will be encouraged to make the right information available in the right ways, so that people with disability and their families can make informed choices and decisions to put their rights into action.³⁰⁰

In addition, the corresponding action is to ensure:

access to safe, welcoming and culturally responsive services are available for vulnerable cohorts of people living with disability. This includes young people, culturally and linguistically diverse people, LGBTIQ+ people and Aboriginal and Torres Strait Islanders.³⁰¹

In Tasmania, ensuring access to communications is part of disability action planning under Accessible Island: Tasmania's Disability Framework for Action 2018–2021.³⁰² In December 2022, the Tasmanian Government advised the Royal Commission planning was underway for the next iteration of this framework, aligned to the ADS.³⁰³ Queensland's Disability Plan 2022–2027 references the policy priorities in the ADS (including that information and communications systems are accessible, reliable and responsive)³⁰⁴ but there are no specific actions attached. The Australian Capital Territory Government is developing a 10-year ACT Disability Strategy and corresponding four-year Action Plan, which is due to be considered in mid-2023 for endorsement and action.³⁰⁵

The need for a unified approach

As the previous discussion shows, governments and organisations are taking a range of steps to improve the accessibility of information and communications for people with disability. This is a positive development. However, the initiatives described in the previous section have not been coordinated. Some are sector- or context-specific, with state and territory initiatives targeting primarily online communications, the justice system and health care. Some focus on a single strategy, such as the use of Easy Read or relying on interpreters.

In the absence of a clear and standardised approach or plan, developed with people with disability, it is difficult for government agencies and people with disability themselves to have confidence that information is accessible to everyone. Our public hearings have shown that many people with disability are still missing out because vital information and communications are not made available in accessible formats.

The option of a new Standard under the *Disability Discrimination Act 1992* (Cth)

Disability standards under the *DDA* are legislative instruments, created by the Commonwealth Attorney-General. They have a five-year review period.³⁰⁶ Section 32 of the *DDA* makes it unlawful to contravene a disability standard.³⁰⁷

The Australian Government has previously considered establishing information and communications standards under the *DDA*.³⁰⁸ In 1996, the Attorney-General's Department

published a discussion paper that proposed different formats that could be covered by the standards. These included materials produced in print, computerised information, broadcast information, telephone communications and face-to-face communications.³⁰⁹ The proposed standards were not progressed, but it is not clear why.

There has been some support for a disability standard on information and communications. At Public hearing 4, Professor Trollor recommended 'a minimum service standard should be set which ensures all health information, and all mainstream health services information, including commonly utilised forms and patient information, should be available in an accessible format'.³¹⁰ Also, the Australian Civil Society Shadow Report response to the CRPD Committee's Review in 2019 recommended the development of, 'Information and Communication Standards that require information to be fully accessible and communication supports to be routinely available'.³¹¹

In its *Human rights and technology final report*, the AHRC recommended the creation of Digital Communication Technology Standards under section 31 of the *DDA*.³¹² Many stakeholders, including Blind Citizens of Australia and the Australian Communications Consumer Network, endorsed the creation of this standard.³¹³

However, in its *Free and equal* report the AHRC raised concerns about the lack of appropriate accountability mechanisms to ensure implementation of existing standards. Compliance with a disability standard can only be enforced if a 'person aggrieved' brings an action for a breach.³¹⁴

International experience suggests that legislated standards are not by themselves sufficient to ensure accessible information and communications. In the United Kingdom, for example, the Accessible Information Standard (UK Standard) applies to service providers across the National Health Service and adult social care system.³¹⁵ The UK Standard has been reviewed but the findings are not yet public.³¹⁶ However, a coalition of disability organisations in the UK has identified the need for improvements, with a survey finding '77% of people with accessible information needs reported rarely or never receiving information in accessible formats'.³¹⁷

In the United States, the *Americans with Disabilities Act 1990* imposes a duty on state and local government services, and business and non-profit organisations servicing the public, to ensure communication with people with disability is 'equally effective' as communication with people without disability.³¹⁸ The US Department of Justice has recognised that staff training is critical to ensuring the success of these provisions: 'Covered entities may have established good policies, but if front line staff are not aware of them or do not know how to implement them, problems can arise.'³¹⁹ A study conducted in Massachusetts also found that workforce training was needed for effective communication between healthcare professionals and patients with disability.³²⁰

The AHRC referred to concerns that:

the process of introducing standards into Parliament 'can be lengthy and ridden with obstacles'. It requires complex consultation processes and regulatory impact processes, including consulting with all Australian governments. As a result, binding standards can be resource- and time-intensive to create. Standards may also

‘freeze the nature of compliance to a minimum standard and may not encourage best practice’.³²¹

The AHRC expressed the view that ‘the current review and enforcement processes are not sufficient to ensure standards are effective’ in creating systemic change.³²² As we have noted, international experience shows that standards are not enough – workforce training and awareness raising are needed too.

In light of these considerations, we do not propose the immediate introduction of a new disability standard on information and communications. Instead, we propose an Associated Plan under the ADS, discussed in the next section.

A plan to promote accessible information and communications

We consider a plan should be put in place to provide accessible information and communications across Australia by bringing together and building on existing initiatives. This plan should focus on practical application of legal obligations and clarify the roles of various stakeholders.

In its response to the CRPD Committee’s decision in *Henley v Australia* (see Section 1.2, ‘International human rights obligations’), the Australian Government referred to the ADS.³²³ As outlined earlier, the Australian Government said the Minister for Communications will develop an ‘Associated Plan’ under the ADS that will be ‘the vehicle for addressing access to communications technologies’.³²⁴

Associated Plans under the ADS are ‘strategies, plans, roadmaps and frameworks that focus on improving aspects of Australian life for people with disability and also work to deliver the vision of the Strategy’.³²⁵ Associated Plans have been included under the ADS to ‘provide a more coordinated, long-term approach to how governments work to improve outcomes for people with disability’.³²⁶ For example, the Disability Employment Strategy is an Associated Plan under the ADS.³²⁷

We welcome the commitment from the Australian Government, following the *Henley v Australia* decision, to develop an Associated Plan on access to communications technologies.

However, we recommend the scope of the Associated Plan be expanded to cover accessible information and communications for people with disability more broadly. This should be in line with Australia’s obligations under article 21 of the *CRPD* and the duty to provide accessible information under our proposed Disability Rights Act (see Volume 4). The Associated Plan should be developed and agreed to by the Australian Government and state and territory governments. In developing and implementing the Associated Plan, the Minister for Communications should work with the Disability Reform Ministerial Council and relevant state and territory ministers.

The Associated Plan should be co-designed with representative organisations of people with disability and in consultation with organisations representing people from culturally and linguistically diverse backgrounds and disability service providers. Local governments, including those representing particularly diverse communities, may also be well placed to contribute to the development of the Associated Plan.

The Associated Plan should consider information and communications across a range of contexts, settings and situations. It should take account of the needs of particular population groups and the critical differences between jurisdictions.

A number of existing initiatives and commitments are limited to one or a few accessible formats. We recommend that the Associated Plan encompass a broad range of modes of communication. At a minimum, the Associated Plan should include how and when to provide material by means of Easy Read, Easy English, Auslan, live and closed captioning, braille or audio description. The role and importance of these formats were discussed at a number of our public hearings.³²⁸ The Associated Plan should consider digital accessibility, in particular, compliance with the Web Content Accessibility Guidelines.

The Associated Plan should provide ways for people with disability and specialist organisations to be involved in producing accessible information. Witnesses at Public hearings 5 and 12 emphasised the importance of this to ensure information meets their needs.³²⁹ In Public hearing 5, Dr Meltzer stated:

where information is to be made accessible, it needs to include people with disability in the production process right from the beginning ... because the process will be richer and more accurate with their feedback and their capacity to drive what happens in a way that's going to be useful for them.³³⁰

Recommendation 6.1 A national plan to promote accessible information and communications

The Australian Government and state and territory governments should develop and agree on an Associated Plan in connection with Australia's Disability Strategy 2021–2031 to improve the accessibility of information and communications for people with disability. The Associated Plan should be co-designed with people with disability and their representative organisations. It should be finalised by the end of 2024.

The Associated Plan should:

- consolidate and build on existing initiatives and commitments by governments
- recognise the diversity of people with disability and the many formats and languages that people may require information to be provided in

- consider the roles of various stakeholders, including the Australian Government, state and territory governments, disability service providers, disability representative organisations and organisations representing people from culturally and linguistically diverse backgrounds
- focus, in the first instance, on information and communications about preparing for and responding to emergencies and natural disasters, and public health
- include targeted actions to ensure access to information and communications for people with disability in the criminal justice system; supported accommodation, including group homes; Australian Disability Enterprises; and day programs
- identify and allocate appropriate funding and resources for delivery
- include mechanisms for review and public reporting of progress made against the Associated Plan.

1.5. Interpreters

People with disability may also need access to appropriately qualified and skilled interpreters to access services and participate in community life. The role of an interpreter is to enable spoken or signed communication between two or more people who do not share the same language or culture.³³¹

A broad range of people with disability may require interpreters. These include members of the Deaf and Deafblind community, First Nations sign language users and people from culturally and linguistically diverse backgrounds. The importance of interpreters in various contexts is also discussed in Chapter 4 of this volume, as well as in Volume 7.

Auslan interpreters

Deaf community access to Auslan and Auslan interpreters

... if you have no language, you don't know what's right and what's wrong ... having no language means you might be more willing to accept things as normal, that neglect is an experience that everybody experiences.³³²

The Deaf community is diverse and employs several different languages and communication methods. Some members of the community are bi-modal bilingual, with fluency in both Auslan and spoken and/or written English. Others primarily use Auslan and may have limited fluency in English.³³³ Auslan is a distinct language with its own structure, grammar and syntax. It is distinct from Signed English, which attempts to mirror the grammar of and reflect the spoken English language.

In the 2021 Census, 16,242 people selected Auslan as the language they use at home (of whom 14,924 were aged 0 to 64).³³⁴ The Australian Network on Disability considers 30,000 people to be a more reliable estimate.³³⁵

At Public hearing 29, we heard about the importance of Auslan to the Deaf community. Access to Auslan plays a critical role in the development of language and identity and gives people an opportunity to connect with the Deaf community and experience Deaf culture.³³⁶ Jen Blyth, CEO of Deaf Australia, told us ‘there is that shared experience and connection through language. And that’s what the Deaf community is essentially about’.³³⁷ She said being Deaf is something that should be celebrated: ‘You are going to be part of an amazing community. You can be part of this amazing world with a language, a culture, your own norms.’³³⁸

Mr Brett Casey, CEO of Deaf Connect, spoke about the relationship between Auslan and the development of Deaf identity or ‘Deafhood’:

Deafhood is about a journey for a Deaf individual to embrace culture, language, and it might be a little bit opposite to the term deafness. So, deafness is usually defined by a deficit model. Something that’s wrong. But Deafhood is about, ‘I accept me for who I am. I am a whole person. I connect with a whole community, and I use sign language to communicate with my colleagues and peers as well as my friends and the broader community.’³³⁹

Access to Auslan is particularly important during early childhood to ensure appropriate language acquisition. However, we heard that parents of deaf children are often discouraged by health professionals from providing their child with access to Auslan.³⁴⁰ This advice is informed by a medical deficit model that focuses on ‘fixing’ or ‘solving’ the child not being able to hear, making the child speak, and assimilating them into a ‘hearing world’.³⁴¹

When a deaf child is denied access to Auslan they are at particular risk of language deprivation.³⁴² Language deprivation occurs when a deaf child is denied full access to language during the first five years of their life.³⁴³ It can have significant consequences. Dr Breda Carty AO explained:

When these neural pathways for language do not develop naturally within the first few years of life, language acquisition becomes harder. The longer the delay, the greater the risk that a child will experience language deprivation – not only is future language acquisition very difficult, but there are knock-on effects on cognition, social development, theory of mind, ability to cope with ambiguity and complexity, and mental health.³⁴⁴

Language deprivation is linked to poor educational outcomes, mental health issues, greater challenges engaging with the community more generally, and an increased risk of exposure to violence, abuse, neglect and exploitation.³⁴⁵ It also impacts an individual's ability to identify and report maltreatment.³⁴⁶

The medical deficit model and the impact of language deprivation in education settings are further discussed in Volume 7.

Deaf Australia noted in its submission that 'because the majority of Australian citizens are not fluent in Auslan, Deaf people are required to use Auslan interpreters in a variety of environments'.³⁴⁷ This includes essential services, such as health, education and the justice system.

Additionally, we heard that a Deaf person will sometimes use an Auslan interpreter and a Deaf Interpreter, who provides additional communication support. A Deaf Interpreter is a Deaf person who is skilled transferring meaning between Auslan and written English, as well as other signed languages.³⁴⁸ They work together with Auslan interpreters. There are many reasons why a Deaf person may require the additional communication support. These reasons include the Deaf person:

- being deafblind
- having a mental illness
- having additional disabilities, including both intellectual and physical disabilities
- not being fluent in Auslan (including because they migrated from another country or did not have access to sign language from a young age)
- having experienced a traumatic situation or crisis.

Auslan interpreters (including Deafblind interpreters, First Nations sign language interpreters and Deaf Interpreters) all play an essential role in ensuring accurate information is provided in a range of situations, including medical, legal, educational and employment settings.

Deafblind community and Auslan interpreters, Deafblind interpreters and communication guides

The term 'd/Deafblind' refers to people who have some hearing and vision, as well as people who are completely deaf and blind. It is difficult to accurately state the incidence of deafblindness in the community due to the broadness of the classification and diversity of conditions the term captures. Figures range from 0.2 per cent to 3.3 per cent of the population. In Australia, this equates to approximately 100,000 people. Of these, two thirds are over the age of 65 years. According to a study cited by Deafblind Australia, about 36 per cent of people aged over 85 are d/Deafblind.³⁴⁹

The most common forms of communication that people who are d/Deafblind in Australia use are:³⁵⁰

- speech, oral and aural communication
- sign language including a variety of ways of receiving sign language such as close range, visual frame and tactile, hand-over-hand signing
- tactile fingerspelling.

At Public hearing 29, Mr Ben McAtamney, a qualified Auslan interpreter and representative of Deafblind Australia, described the specialist role of a Deafblind interpreter:

it requires modification of the language in terms of the mode in which it's presented, and that is dependent upon the person's specific vision needs ... There is also an additional emphasis placed on interpreting the environmental information when working in a Deafblind context ... cues that come from the environment that may not need to be explicitly articulated when someone has full visual access, they then become part of the interpreter's responsibility or part of ... what the Deafblind person is expecting from their interpreters.³⁵¹

In addition to interpreters, people who are d/Deafblind may require a communication guide (also known as a Comm Guide).³⁵² At Public hearing 29, Mr Joe Monteleone said the role of a communication guide is to 'guide the person in the environmental space' and 'provide communication support'.³⁵³ Mr Monteleone told us he often uses a communication guide when he is unable to access an appropriately qualified and skilled Deafblind interpreter.³⁵⁴

Submissions highlighted the value and importance of communication guides for members of the d/Deafblind community for a range of activities. One Deafblind person said, 'the only way I can do administrative tasks, engage with hearing population, socialise with non-deaf people, do leisure tasks, cook food – and so much more – is with the support of a Comm Guide and/or interpreter'.³⁵⁵ Another Deafblind person said:

The impact on my mental health without the use of interpreters is profound. I would particularly feel the impact at night because without the comm guide I cannot see, which means I cannot socialize.³⁵⁶

There is no official framework or policy outlining the qualifications necessary to be a communication guide. Members of the Deafblind community and their supporters have shared their views, ideas and preferences as to what qualifications should be required for this role.³⁵⁷ They have also expressed concern about the lack of training and regulation. Mr McAtamney said a lack of training and regulation means there is 'no guarantee that the person who shows up is going to be able to do the job they have been hired to do'.³⁵⁸

Formal accreditation process for qualified interpreters

At Public hearing 29, we heard evidence about the pathways to become an interpreter. A person has to learn a language or be a native speaker or signer, undertake a Diploma of Interpreting, and then be accredited through the National Accreditation Authority for Translators and Interpreters (NAATI). NAATI sets and maintains national standards for the translating and interpreting sector. It is the only organisation to issue credentials or certification to people who wish to work in the profession.³⁵⁹

In the case of NAATI accreditation for Auslan and most spoken languages interpreters, an interpreter becomes a Certified Provisional Interpreter first and then a Certified Interpreter.³⁶⁰ The Certified Interpreter accreditation reflects a higher level of skill and experience.³⁶¹ NAATI also offers accreditation for Deaf Interpreters by providing Recognised Practising Deaf Interpreter accreditation.³⁶² Additionally, NAATI has recently commenced specialised certifications for settings such as medical and legal settings for Auslan and ‘major community languages’.³⁶³

After completing a Diploma of Interpreting, those seeking to become Certified interpreters may also choose to complete a Postgraduate Diploma in Auslan-English Interpreting.³⁶⁴ However, this is not compulsory and postgraduate courses are not widely available.³⁶⁵ In addition, Auslan is not offered as an optional course for undergraduates at Australian universities in the same way as other spoken languages.³⁶⁶

Witnesses at Public hearing 29 emphasised that Deafblind interpreting is a specialised skill. After becoming a Certified Provisional Interpreter, further study is required to develop the necessary skills to be a Deafblind interpreter.³⁶⁷ However, there are limited opportunities and pathways. In his evidence, Mr McAtamney told us training for Deafblind interpreters is deprioritised within the interpreting sector:

Unfortunately, it's still, I think, largely conceived of as an optional specialisation within the interpreting sector, as opposed to something that should be a part of every certified provisional interpreter's skill set once they are qualified. So, it really is luck of the draw, and people overwhelmingly are forced to structure their lives around what and when the support is available, as opposed to any other goal that they might have.³⁶⁸

Significant shortage of Auslan interpreters

Evidence from Public hearing 29 demonstrated the chronic shortage of Auslan interpreters. Most Auslan interpreting agencies report not being able to fill jobs as requested on a regular basis.³⁶⁹ There is also a shortage of specialist Deafblind interpreters and communication guides. Mr McAtamney said:

there's nowhere near enough Auslan interpreters nationally to provide for current demand. And unfortunately for Deafblind people, their options are further limited by the fact that that already small pool of people is not in full possession of the skills and knowledge to provide for their needs.³⁷⁰

Mr McAtamney described the shortage of Auslan interpreters as ‘a national skills emergency’ and ‘a problem that’s putting people at risk ... endangering their safety’.³⁷¹

At Public hearing 29, Ms Rebecca Adam, then CEO of Access Plus, described the particular challenges experienced by d/Deaf and hard of hearing people, including deaf First Nations people, in Western Australia.³⁷² She said, ‘For every 10 interpreter requests that Access Plus receives, it is able to make arrangements for 6 of them.’³⁷³

Interpreters may be required in a range of settings including medical, legal, education, employment and social services settings.³⁷⁴ In these contexts, unfamiliar words and concepts may be used.³⁷⁵ Specialist qualifications in these areas can ensure that interpreters have sufficient understanding of the subject matter, key terms and concepts to provide an accurate representation of the information provided. NAATI has commenced specialised certifications for settings such as medical, legal and conferencing for Auslan and ‘major community languages’.³⁷⁶

The lack of Auslan interpreters is not a new issue. Evidence in Public hearing 29 acknowledged the lack of research to quantify the demand-supply gap.³⁷⁷ However, there is some information available to demonstrate the small number of interpreters in Australia and the uneven geographical spread.³⁷⁸ Table 6.1.1 shows that most accredited Auslan interpreters are in Victoria and New South Wales and that there is a significant lack of accredited interpreters in other states and territories.³⁷⁹

Table 6.1.1: Auslan interpreters in states and territories, as at March 2022

State	Number of Auslan interpreters
Australian Capital Territory	9
New South Wales	155
Northern Territory	3
Queensland	148
South Australia	51
Tasmania	14
Victoria	197
Western Australia	77
Total	654

Source: Per Capita July 2022.

There is also a lack of Deaf Interpreters. As of March 2022, there were 36 Recognised Practising Deaf Interpreters and 27 Certified Provisional Deaf Interpreters.³⁸⁰ Deaf interpreters play a key role in facilitating communication with deaf refugees and migrants. Deaf Australia noted in its submission that Deaf refugees may not have had the opportunity to learn sign language for a number of reasons. Therefore, they arrive in Australia with limited language skills.³⁸¹ This creates a unique challenge for interpreters who are only trained in Auslan. Deaf Australia advises that in these circumstances it is ideal to use a Deaf interpreter to reduce misunderstanding and miscommunication.³⁸² However, Deaf interpreters are also in demand to support Deaf Australians.

The NDIS has further increased demand. As Ms Michelle Stark explained in her evidence at Public hearing 29, when the NDIS rolled out ‘people with packages could use their funds to engage interpreters in domains that they had never had access to interpreters before. So, the demand increased.’³⁸³

Deaf Australia also noted the impact of the NDIS:

The NDIS has enabled Deaf people to be able to have interpreters at any time and any place, which has increased demand for interpreters – making this a ‘seller’s market’ in that interpreters can pick and choose jobs at varying price points, regardless of the Deaf person’s requirements and preferences.³⁸⁴

Notably, the NDIS Workforce Strategy is silent on the need for Auslan interpreters.

The shortage of Auslan interpreters and uneven geographical spread, combined with the impact of the COVID-19 pandemic, has resulted in an increasing number of Deaf people using Video Remote Interpreters to access services and supports.³⁸⁵ This is especially the case for Deaf people living in regional and rural communities.³⁸⁶ As explained by Deaf Connect in its submission, ‘Using VRI and removing travel time frees up an already limited resource and allows participants to access interpreters in regions where there are none or very few available.’³⁸⁷

Having a Video Remote Interpreter is better than having no access to an interpreter at all. However, many Deaf people still prefer in-person services.³⁸⁸ This is especially the case for older Deaf people and members of the Deafblind community. Deaf people from low socio-economic backgrounds may be unable to use Video Relay Interpreting services due to a range of factors – for example, a lack of digital literacy skills,³⁸⁹ lack of technological devices³⁹⁰ or lack of internet connection.³⁹¹

In addition to an overall shortage, there is also a lack of diversity within the current pool of Auslan interpreters.³⁹² Deaf Australia noted:

There are not many diverse interpreters in this community. It is a predominantly white, female or female-identifying industry ... There are only approximately four or five First Nations interpreters in Australia, but it is unclear how many are NAATI qualified.³⁹³

Therefore, most Auslan interpreters may not be able to provide culturally safe services, particularly for Deaf First Nations people and Deaf people from culturally and linguistically diverse backgrounds.³⁹⁴ Deaf Australia quoted a Deaf First Nations person who reflected on their experience using an Auslan interpreter at a family event:

I am Aboriginal. I went to a family event with an interpreter who was white. My family was weird when they were interacting with me. My father later told me I 'sounded white', and this made them feel uncomfortable.³⁹⁵

Expression Australia's submission stated awareness of intersectionality is a relatively new concept in the Deaf sector. It emphasised that much needs to be done to address this:

According to the World Federation of the Deaf (2022), the deaf community is one of the most intersectional communities on Earth with representation in each Indigenous, ethnic, racial, linguistic, religious, identity-based, and cultural group. For decades, much of services available for deaf people has solely focused on the 'straight white deaf person' without acknowledging other identities within the deaf community, which meant other deaf people who do not identify as such have missed out on accessing relevant services and working with organisations to ensure that they receive appropriate support.³⁹⁶

Adverse consequences of the lack of Auslan interpreters

The shortage of appropriately qualified and skilled Auslan interpreters results in many Deaf and Deafblind people not being able to access essential systems, services and supports.³⁹⁷ We have heard about poorer educational and health outcomes resulting from a lack of interpreters, as well as implications for people in the justice system.

A deaf child's education is only as good as their interpreter's qualification and skill set.³⁹⁸ At Public hearing 29, Mr Casey and Jen said there is an increasing number of schools employing educational interpreters with no formal qualifications and/or a lack specialist training for working with children.³⁹⁹ Jen told us:

Sometimes some of them are NAATI certified. Some might be newly certified and some aren't certified, but often they are not trained to work with children. They don't necessarily have the skills of how to navigate that situation, and children don't often know how to work with educational interpreters.⁴⁰⁰

Research conducted on behalf of the Australian Government in 2004 considered 50,000 medical appointments for which an interpreter was required. Family and friends were required to serve as interpreters in 30 per cent of these appointments. Twenty-nine per cent of appointments were either rescheduled or simply continued in the absence of an interpreter.⁴⁰¹

In Public hearing 27, evidence demonstrated that both youth and adult prisoners experience long wait times to access Auslan interpreters.⁴⁰² This means that prisoners are often unable to

participate in activities,⁴⁰³ have a limited ability to communicate with their solicitor⁴⁰⁴ and potentially serve more time than they would have received under sentence.⁴⁰⁵

Responses to the *Criminal justice system issues paper* outlined the consequences of a lack of interpreters for d/Deaf people in the criminal justice system.⁴⁰⁶ These include:

- impacts on the admissibility of evidence gathered from interviews with people who experience communication barriers or adduced in court proceedings⁴⁰⁷
- Deaf people in custody potentially facing punishment for failing to follow procedures that were not communicated to them in an accessible way.⁴⁰⁸

Additionally, at Public hearing 29, Ms Adam, then CEO of Access Plus, noted the significant impacts on First Nations people of the lack of interpreters in Western Australia.

These included being arrested and detained ‘for two or three days at a time’ without understanding the charges against them or being able to access an interpreter.⁴⁰⁹

We have also heard evidence of family members, including children with Deaf parents, being called upon to act as interpreters in a range of settings.⁴¹⁰ Della Goswell spoke about interpreting for her Deaf parents in many situations from car repairs to religious occasions and parent teacher interviews.⁴¹¹ She recalled feeling involved in ‘very grown-up’ things but also noted it placed her in ‘quite a controlling position’.⁴¹²

Deaf Australia submitted that the lack of interpreters and related reliance on ‘inappropriate or inexperienced interpreters, speech-to-text apps or family and friends’ results in:⁴¹³

- reduced health outcomes including physical harm and delays in investigations and diagnosis, because an interpreter was not used during consent for procedures, in counselling about hospital discharge medications and in obtaining proper medical history
- misleading information and miscommunication, and reduced privacy considerations or ethical breaches (given that unaccredited interpreters are not bound by a professional code of ethics).

Structural barriers driving the interpreter shortage

Overall, interpreter training opportunities tend to be centralised in capital cities. People who live in regional areas are often not able to access courses. Challenges are further compounded for Auslan training given there is a limited number of people who are capable and qualified to teach Auslan to emerging interpreters.⁴¹⁴

Della Goswell, an expert witness, spoke about the challenges of progressing from a Certified Provisional Interpreter level to a Certified Interpreter. She noted that postgraduate courses are available in Auslan and spoken language to help interpreters make this step.⁴¹⁵ However, in the case of Auslan, attending Macquarie University in Sydney may be very difficult for people with other work or family commitments.⁴¹⁶

We have heard many reasons why it can be challenging to retain Auslan interpreters and attract new people to the profession. Once someone becomes a qualified interpreter, there is a lack of full-time employment opportunities, and the work is ‘very casualised’.⁴¹⁷ In addition, the nature of the work makes it very difficult to work 40 hours per week, given the need for regular breaks to avoid overuse injuries.⁴¹⁸

Deaf Connect noted in its submission that there are a number of features that make Auslan interpreting ‘an unattractive long-term career prospect’:⁴¹⁹

- It can be seasonal, with demand peaking during TAFE/university semester time.
- Some interpreters feel pressured by employers to accept poor working conditions (such as working long shifts alone), which create stress and can cause injury.
- While the hourly rate is high, the number of hours that are physically possible in a week are limited (25 hours per week is recommended). This rarely equates to a full-time professional wage.
- Preparation time for many assignments can be substantial, and is very rarely paid.
- Interpreters, especially freelance interpreters, tend to work alone and often lack collegial support.

Similar barriers have been highlighted by recent parliamentary inquiries. The New South Wales Legislative Council Procedure Committee’s 2022 Inquiry into Auslan Interpretation for Broadcasting examined the shortage of Auslan interpreters in New South Wales.⁴²⁰ The committee found the underlying drivers contributing to the shortage include a lack of awareness, a lack of professional training and development opportunities, the time it takes for individuals to acquire the highest accreditation levels (approximately 10 years), and a lack of consistent work.⁴²¹

In 2023, the Legislative Assembly for the Australia Capital Territory published its *Inquiry into access to services and information in Auslan* report, which also recognised the significant shortage of Auslan interpreters:

A fully-certified NAATI-qualified interpreter is able to provide services in a range of complex and specialised settings and there is only one such interpreter in the ACT who is semi-retired.

There are an additional eight NAATI Certified Provisional Interpreters in the ACT who are qualified to facilitate communication of non-complex messages in limited settings.⁴²²

The report noted ‘the cost of Auslan training, in addition to there being no local provider makes it difficult for those living in the Australian Capital Territory to study to become an Auslan interpreter’.⁴²³ Opportunities to pursue a career as an Auslan Interpreter in the Territory were reduced in 2015 when the Canberra Institute of Technology stopped offering Auslan courses.⁴²⁴ Residents are able to access certified Auslan training through Deaf Connect, but the report notes that costs are ‘comparatively higher than other states’.⁴²⁵

Accredited interpreters are required to undertake professional development to maintain their accreditation.⁴²⁶ However, Monash University research has identified that gaps in professional development opportunities also act as a barrier to enhancing the skills and capabilities of the existing workforce. Other barriers include cost, a lack of suitable opportunities (including some being described as ‘too basic’) and a lack of communication about available opportunities.⁴²⁷ The research also found there is a need for more professional development in health and legal topics, as well as interpreter self-care. Curricula need to be more specialised, skills-focused and relevant to current workplace requirements.⁴²⁸

Actions and commitments to address the shortage of interpreters

State and territory governments have taken action and made commitments to address an overall shortage of interpreters in Australia, including Auslan interpreters.

Subsidies are provided under the Victorian Government’s 2023 Interpreter Scholarship Program,⁴²⁹ and the Victorian Skills Gateway.⁴³⁰ The Victorian Budget 2022–23 provided more than \$4 million to make the Diploma of Auslan and the Advanced Diploma of Interpreting (Auslan stream) available fee-free from 2023.⁴³¹

Subsidised TAFE courses are also available in South Australia under the Skills SA initiative. South Australian residents can apply for government-funded subsidies for a number of interpreting and translation courses, one of which is Auslan.⁴³²

In October 2021, the Northern Territory Government committed funding of \$89,200 to support scholarships for Auslan interpreter courses, and \$360,000 over three years to provide a full-time Auslan interpreter to be based in the Northern Territory.⁴³³

In 2022, the Tasmanian Government offered Interpreter Training Scholarships to local interpreters wanting to enrol into the Interpreter skills Online Training for NAATI Certification.⁴³⁴ This program intends to ‘increase the supply and quality of accredited interpreters, particularly for languages in demand’. The priority languages covered under this scholarship include Auslan.⁴³⁵

In 2022, the Western Australian Government funded 16 Interpreting Scholarships. This scholarship was limited to ‘in-demand languages’, which did not include Auslan.⁴³⁶

The New South Wales Government recently allocated additional funding to an interpreter scholarship program. The program will provide 450 scholarships for emerging and existing interpreters and translators per year until 2024.⁴³⁷ However, it is unclear whether this scholarship program targets specific languages and whether it includes Auslan/sign language interpreters.

In Queensland, the Multicultural Action Plan refers to upskilling front-line interpreting staff and investing \$730,000 over three years from 2021–22 to boost the supply of interpreters in priority languages (approximately 100 interpreters). However, it is unclear whether this includes Auslan.⁴³⁸

In addition, the National Indigenous Languages Interpreting Advisory Committee was established in 2016 to provide advice to NAATI on issues in First Nations interpreting.⁴³⁹ NAATI has also implemented the Indigenous Interpreting Project to:⁴⁴⁰

- increase the number of certified First Nations interpreters and examiners
- increase the range of First Nations languages for which there are certified interpreters
- increase the accessibility of interpreting resources for First Nations interpreters and organisations.

There are a number of positive developments in the initiatives listed above. However, the shortage of Auslan interpreters remains.

Actions to increase the supply of interpreters

Della Goswell told Public hearing 29 about successful fast track courses for qualification of people with language skills. She noted other potential pathways, such as more ‘scaffolded stepping stones’ and short courses to step between levels of accreditation.⁴⁴¹ Other suggestions from witnesses included:

- mentoring between Deaf people and interpreters and creating accessible pathways for d/Deaf students to enter the profession of Deaf interpreting⁴⁴²
- increasing public sector employment of native Auslan users and interpreters, employing people who are d/Deaf or hard of hearing who can assist with better understanding the needs of d/Deaf clients in frontline services, and including Auslan in job descriptions.⁴⁴³

As Ms Adam, then CEO of Access Plus, noted at Public hearing 29:

if governments are going to advance goals such as inclusion and empowerment rather than just talk about them, they will need to set publicly acknowledged goals to employ appropriately skilled staff.⁴⁴⁴

Witness evidence within the NSW Legislative Council Procedure Committee’s *Auslan interpretation for broadcasting* report identified the link between exposure to Auslan and choosing Auslan interpreting as a career.⁴⁴⁵ The NSW report also highlighted the need to increase professional development and career opportunities to address workforce shortages.⁴⁴⁶

Need for a comprehensive workforce strategy

To mitigate the risk of violence, abuse, neglect and exploitation of people with disability from culturally and linguistically diverse communities, including people who are Deaf and Deafblind, it is necessary that the interpreter shortage be addressed.⁴⁴⁷ While some actions have been taken, significantly more investment is needed.

Public hearing 29 demonstrated the need for a comprehensive workforce strategy to increase the number and quality of Auslan interpreters. A range of actions is needed over the short, medium and long-term to increase participation in interpreting courses, encourage retention of qualified interpreters and ensure the interpreting workforce includes sufficient specialisation to support its clients across a full range of service settings. Specific initiatives are also needed to promote a more diverse and inclusive workforce and ensure professional development supports an ongoing improvement in skill levels and quality.

Many witnesses at Public hearing 31, 'Vision for an inclusive Australia', emphasised that government policies and practices should be co-designed by people with disability, including those from intersectional backgrounds, and people within the relevant industry.⁴⁴⁸ It is essential that Deaf, Deafblind and First Nations sign language users have direct input into developing the actions that are needed to serve their communities and facilitate access to critical services. As demonstrated above, these communities have a meaningful understanding of relevant gaps within the Auslan interpreting workforce. They are well placed to identify appropriate strategies to address the shortage of appropriately qualified and skilled sign language interpreters. The same can be said for NAATI representatives and accredited Auslan interpreters.

The NDIS Quality and Safeguards Commission (NDIS Commission) may also have a role to play, to ensure that actions are aligned with the future NDIS Workforce Strategy.⁴⁴⁹

We note that changes should be implemented in a staged approach. In Public hearing 29, the tension between the increased use of interpreters for government services and the subsequent impact on other areas that also require translation was noted.⁴⁵⁰ This was also highlighted by the NSW Legislative Council Procedure Committee's *Auslan interpretation for broadcasting* report.⁴⁵¹

The Disability Reform Ministerial Council would be well placed to lead the development of the strategy, given the need for a coordinated national approach as well as targeted actions to address shortages and meet specific needs in individual states and territories.

Recommendation 6.2 Increase the number of Auslan interpreters

The Australian Government and state and territory governments, through the Disability Reform Ministerial Council, should commission the development of a workforce strategy to increase the number and quality of Auslan interpreters.

The strategy should:

- be based on a robust demand-supply analysis to quantify the current gaps and shortages in interpreting services. This includes analysis of qualifications, specialisations, geographic coverage, and the availability and use of face-to-face interpreting and Video Remote Interpreting

- include costed initiatives to:
 - increase the number of Auslan interpreters, including the provision of scholarships and stable ongoing employment opportunities, particularly in under-serviced areas
 - support specialisations in health, legal and other critical sectors (including minimum qualifications)
 - provide ongoing professional development and industry standards to support a high-quality interpreter workforce
 - increase and retain Auslan interpreters who are First Nations or from culturally and linguistically diverse backgrounds
 - raise awareness and promote pathways to becoming an Auslan interpreter.

The strategy should be developed by September 2024, and implementation of the strategy should begin by January 2025.

First Nations sign languages

First Nations sign language systems

There are a number of sign languages employed by First Nations peoples that differ from both English and Auslan. These follow First Nations spoken language groups and are culturally bound. Research commissioned by Deaf Connect and Deaf Australia estimates there are over 300 First Nations sign language systems.⁴⁵²

In Public hearing 25, 'The operation of the NDIS for First Nations people with disability in remote and very remote communities', we heard from Ms Jody Barney, a Birri-Gubba Uragan and South Sea Islander woman.⁴⁵³ Ms Barney is Deaf and communicates using Auslan, various forms of First Nations sign languages and written English.⁴⁵⁴ She told us many First Nations sign language systems 'form part of a multi-modal communication system, where they are used for cultural purposes' in a specific community.⁴⁵⁵

Ms Barney also noted 'for some Deaf and hard of hearing First Nations people a First Nations sign language system is their first, and only, language'.⁴⁵⁶ Ms Barney also noted the impact of western language systems, such as Auslan, in this way:

as First Nations Deaf and Hard of Hearing people utilise western language systems, the use of their preferred sign language is diminished. Often this is due to the lack of awareness generally and a need for training to understand complex language needs of those who use First Nations Sign Language systems.⁴⁵⁷

Lack of First Nations sign language interpreters

At Public hearing 25, Ms Barney referred to the lack of interpreters available for Deaf First Nations people.⁴⁵⁸ In doing so, she also pointed out there were no Deaf First Nations Interpreters working at Public hearing 25, which took place in Alice Springs:

The difference for First Nations Deaf communities is that we don't have a pool of interpreters available who are experienced and knowledgeable and well trained and qualified to be able to work in the same kinds of areas that Auslan interpreters do ... we need more of an investment to be able to increase that pool, to be able to improve access for people.⁴⁵⁹

Ms Barney also noted the lack of First Nations sign language interpreters is, in part, driven by a lack of recognition of First Nations sign languages:

It's not core business for interpreters, for interpreting services, to think [about] First Nations Deaf and hard of hearing people. So because the system only recognises Auslan as the language for Deaf people in Australia and they provide access to Auslan interpreters, the view is that the work ... is done, the job is done.⁴⁶⁰

At Public hearing 27, Ms Barney also said Deaf First Nations people in prisons are not often provided with a qualified sign language interpreter.⁴⁶¹ Instead they are provided with a 'spokesperson' or 'buddy' who speaks on their behalf.⁴⁶² This reliance on a spokesperson or buddy can create issues from a confidentiality and cultural safety perspective.⁴⁶³ Also, if the spokesperson or buddy 'dies, or is moved to another prison' then the deaf person 'is left without someone to tell them what's going on. This means they become vulnerable in the prison system.'⁴⁶⁴

Research commissioned by Deaf Australia and Deaf Connect also highlighted the lack of First Nations sign language interpreters. The research found there is a 'dearth of interpreters' with knowledge of both First Nations sign languages and English. This may make service access challenging for Deaf First Nations people and puts the cultural safety of service delivery at risk.⁴⁶⁵ This aligns with evidence in Public hearing 27, which showed there were frequent difficulties in accessing First Nations sign language interpreters for detainees with a culturally-based developed sign language that may be specific to their family or community.⁴⁶⁶

The lack of First Nations sign language interpreters is part of a broader issue. Significant investment is needed to grow the First Nations workforce supporting people with disability.⁴⁶⁷ We discuss this further in Volume 9, *First Nations people with disability*.

Spoken language interpreters

At Public hearing 29, we heard that unlike Auslan, the NDIS does not fund spoken language interpreters because they are not viewed as directly related to a participant's disability. However, there are some other services that support people with disability who require spoken-language interpreters.

The Translating and Interpreting Service (TIS National) provides services for people who require a spoken language interpreter when interacting with specific government agencies and businesses.⁴⁶⁸ Immediate phone interpreting services are available 24 hours a day, every day of the year.

The Whole of Government Access and Equity Strategy requires Australian Government agencies to provide interpreting services (via the TIS National) and to pay for the associated costs.⁴⁶⁹ Some state and territory governments offer similar interpreting services, such as Multicultural NSW Language Services.⁴⁷⁰

TIS National also delivers the Free Interpreting Service, which provides free access to interpreting for eligible groups, including medical practitioners, pharmacies, allied health professions, non-government organisations providing casework and emergency services, real estate agencies, local government authorities, trade unions and parliamentarians.⁴⁷¹

In October 2022, a pilot program was introduced that provided some privately employed allied health professionals (including psychologists and registered counsellors) with access to the Australian Government's Free Interpreting Services. Under the pilot program, access is available to eligible private sector allied health professionals that provide services in 32 Local Government Areas.⁴⁷²

The National Indigenous Australians Agency provides funding for First Nations language interpreter services.⁴⁷³ These include:

- the Aboriginal Interpreter Service (in the Northern Territory)⁴⁷⁴
- Aboriginal Interpreting WA (formerly Kimberley Interpreting Service)⁴⁷⁵
- the Aboriginal Language Interpreting Service (in South Australia)⁴⁷⁶
- 2M Language Services: Aboriginal and Torres Strait Islander languages Interpreting (in Queensland).⁴⁷⁷

In her evidence at Public hearing 25, Ms Barney noted that, because of a lack of funding, the Northern Territory Aboriginal Interpreter Service does not provide sign language interpreters:

the onus is on the spoken language interpreter to use sign language to try to fit the – to fit with the spoken and sign language interpreters to kind of provide communication access. There's a lot of pressure on them and a lot of responsibility on them.⁴⁷⁸

Lack of spoken language interpreters

While there are services to provide interpreter support, their effectiveness relies upon an adequate supply of interpreters. However, similar to Auslan, there is also a lack of skilled and accredited spoken language interpreters for people with disability from culturally and linguistically diverse backgrounds.⁴⁷⁹ This is particularly evident in rural communities. These shortages are compounded in regional areas, despite new arrivals from emerging communities being settled in these locations.⁴⁸⁰

When a professional interpreter is not available, other members of a community may be forced to step into this role.⁴⁸¹ For example, 'Muzhgan', from the Wise Well Women Community Health Educator Program, is not a qualified interpreter. However, she told us that she often has no choice but to do her best to interpret for her community.⁴⁸²

Because of the lack of interpreters, culturally and linguistically diverse people with disability may choose not to access necessary services and supports. This is often the case when community members, who may not be qualified interpreters, are called upon to interpret. This can be particularly problematic in small communities. Having community members act as interpreters can place both parties in awkward and uncomfortable situations, where private or sensitive information is discussed.⁴⁸³

ADA Australia told us in their response to the *Experiences of culturally and linguistically diverse people with disability issues paper* that people from non-English speaking backgrounds 'regularly encounter challenges with translating and interpreting services'. In particular, they said it may be difficult to find a translator with enough skills and experience in the required language.⁴⁸⁴ As noted, there are many actions underway across states and territories to increase the supply of spoken language interpreters for 'in-demand' languages, reflecting the needs of particular communities. It is appropriate that these strategies are informed by local demographics, which can change over time. However, it is essential that the needs of people with disability from culturally and linguistically diverse backgrounds are included in this analysis, given the available datasets from the Australian Bureau of Statistics.

Disability awareness training is not required for spoken language interpreters

A lack of disability awareness can lead to a breakdown in communication between a person with disability and their interpreter. The University of New South Wales Social Policy Research Centre and the National Ethnic Disability Alliance (NEDA) articulated this point in the research report *Towards best-practice access to services for culturally and linguistically diverse people with a disability*, prepared for the Royal Commission.⁴⁸⁵ Because of their relationship with the Deaf and Deafblind community, Auslan interpreters receive disability awareness training before they obtain their accreditation. For example, Auslan courses require students to develop an awareness of Deaf culture and Deaf protocols for communication.⁴⁸⁶

However, spoken language interpreters are not required to complete disability awareness training as part of their accreditation and ongoing professional development. This means spoken language interpreters may not have an understanding of what disability is and means. They may be unfamiliar with disability-specific terminology. They may also be unaware of the impact of the shame and stigma associated with disability and mental health in some communities.⁴⁸⁷

In their response to the *Experiences of culturally and linguistically diverse people with disability issues paper*, NEDA, People with Disability Australia and the Federation of Ethnic Communities Councils of Australia recommended that NAATI and training providers 'ensure professional and certified interpreters are trained in the use of disability and mental health terminology, and the social model of disability in general'.⁴⁸⁸

Similarly, NEDA and the University of New South Wales Social Policy Research Centre said ‘Interpreters require specific training or instruction related to disability and culture, specific instruction around terminology used in disability’ as well as ‘an understanding of the shame experienced by some communities about disability’. They said this has the potential to become formalised through an accreditation process.⁴⁸⁹

Spoken language interpreters and access to disability services

Many First Nations people with disability and people with disability from culturally and linguistically diverse communities, and their families, need additional, practical support to access and navigate the NDIS. For example, they may need assistance filling in forms, obtaining supportive medical evidence, understanding information in their preferred language and attending appointments.⁴⁹⁰

The NDIA’s Practice Guide – Accessible Communication states that all ‘participants must be supported to communicate in their preferred method in all their dealings’ with the NDIA.⁴⁹¹ It contains considerations for when a participant chooses an alternate preferred method of communication and, importantly, considerations on arranging interpreting services.⁴⁹² Considerations on arranging interpreting services include:⁴⁹³

- understanding whether the NDIS participant speaks a particular dialect
- the need for additional time to prepare for working with an interpreter
- that participants should be given the option to request a specific interpreter
- political, religious and cultural sensitivities which may influence the outcome of an interpreting situation.

However, First Nations people and culturally and linguistically diverse people with disability continue to experience communication barriers when engaging with the NDIA.

First Nations people with disability

At Public hearing 25, we heard evidence from First Nations people with disability and their families from remote and very remote communities as well as from witnesses representing Aboriginal Community Controlled Organisations. Witnesses gave evidence demonstrating that the availability of interpreters for the NDIS is falling well short of what is required:

- Mrs Kunmanara (Margaret) Smith and Ms Cassie Atchison said they have not seen NDIS information translated or interpreted in traditional languages.⁴⁹⁴
- Mrs Bakoi Namok a Torres Strait Islander woman, told us about her family’s experience with the NDIS after her son Simeon had a stroke in late 2021. She said that even though Simeon does not speak good English, he has never been offered a Creole interpreter during planning meetings. She and her son rely on Simeon’s siblings to interpret for them during these meetings.⁴⁹⁵

- Ms Barney said the NDIS does not recognise First Nations sign languages and it is difficult to secure a First Nations interpreter for a Deaf person. Also, often the interpreter will not be funded.⁴⁹⁶
- Dr Lauren Rice said it was important to have locally based interpreters rather than an interpreter on the phone. She said, ‘it has to be somebody who lives here, who says to the family, “This non-Aboriginal person is okay, you can trust them.”’⁴⁹⁷

The NDIA’s Practice Guide – Accessible Communication provides that:

It is the responsibility of the NDIS staff and/or Partner to find and provide an Aboriginal and Torres Strait Islander language translator or interpreter. Aboriginal and Torres Strait Islander language interpretation must be organised based on the participant’s location, through state-based organisations.⁴⁹⁸

The NDIA also has a Practice Guide for Aboriginal and Torres Strait Islander planning support. This practice guide provides guidance for NDIA staff and partners in community who are preparing NDIS plans for First Nations people with disability. The practice guide states that NDIA staff and partners should identify whether the planning meeting should be conducted in English or if an interpreter is required. If an interpreter is required, one should be arranged even if a family member who can speak English is brought to the meeting.⁴⁹⁹ The practice guide also prompts planners to consider if a participant will understand the written plan or whether another method of conveying plan information is more appropriate.⁵⁰⁰ We agree with Counsel Assisting submissions for Public hearing 25, which state that while this guide is useful in theory, work is needed to ensure the aims of the guide are realised in practice.⁵⁰¹

Culturally and linguistically diverse people with disability

Respondents to the *Experiences of culturally and linguistically diverse people with disability issues paper* told us that NDIS participants from diverse backgrounds may not receive adequate supports in their NDIS plans because of communication barriers and a lack of cultural competency.⁵⁰²

At Public hearing 29, Ms Kylie Scoullar told us about the consequences for people with disability from culturally and linguistically diverse backgrounds when an interpreter is not provided during NDIS planning meetings. She referred to the experience of a teenage girl, with a complex genetic disorder and intellectual disability. The teenager and her family are refugees with permanent residence supported by Foundation House. There was no interpreter at the initial meeting to assist the parents to communicate their daughter’s needs. The family did not understand they were responsible for providing supporting documentation and additional information. Therefore, the teenager’s NDIS plan referred to only one of her disabilities and did not meet her needs.⁵⁰³

In a submission, AMPARO Advocacy noted that state and federal language service policies require that funded interpreting services be provided for participants with limited English proficiency. However:

as this is not widely promoted by the NDIA and other government departments, many government employees, NDIS employees and service providers remain unaware of this. Frequently we find that services do not know that free interpreting services are available or, if they do, they are not aware of how to access them.⁵⁰⁴

At Public hearing 29, Ms Sarah Johnson, Acting Deputy CEO, Strategy and Service Improvement at the NDIA, said the NDIA would ensure that interpreters were present in meetings with participants where they were requested and needed. Ms Johnson accepted the possibility of someone falling through the gaps because they do not know who to contact for an interpreter. Ms Johnson indicated that this was a matter to be examined in the work on the new NDIA Cultural and Linguistic Diversity Strategy.⁵⁰⁵ This strategy and its action plan are being co-designed with people with disability from culturally and linguistically diverse backgrounds.⁵⁰⁶ One of the strategy's agreed goals, outlined in the NDIA's Discover Phase Report, is to increase participant and community awareness and use of interpreting services available through the NDIS.⁵⁰⁷ At the time of writing, the strategy had not been finalised.

The Australian Government's response to Counsel Assisting submissions for Public hearing 29 stated:

The NDIA's new business system will significantly redesign NDIS systems and processes. Part of this redesign includes improving the identification of CALD participants within the business system so that more targeted support can be provided.

In late 2022, the NDIA commenced a pilot of its new business system in Tasmania. The new business system includes improved data collection and a visible flag for all participants, nominees and carers that identifies their CALD status, and can be easily viewed on each individual NDIS record. Recorded data also includes a person's primary and secondary language type, as well as their language and interpreter requirements. The new business system is expected to be rolled out nationally commencing throughout 2023.⁵⁰⁸

Need for training and practice change is needed

Interpreters play a critical role in enabling people from culturally and linguistically diverse backgrounds to access the NDIS. However, interpreters require disability awareness training to ensure they have the skills and understanding to work effectively and appropriately with people with disability.

People may miss out on critical supports and services if they are not provided with an interpreter when they require one or if their interpreter is not appropriately skilled and qualified. Improvements are needed in how interpreters are provided and used for disability service provision. However, the NDIS Practice Standards and Quality Indicators for registered NDIS providers are silent on the use of interpreters.

The NDIA should take measures to improve access to and use of interpreters by NDIS Planners, Local Area Coordinators and early childhood partners. The relevant NDIS Practice

Standards and Quality Indicators should be updated to require registered disability service providers to improve access to and use of interpreters for people with disability who require them. The NDIS Commission should update the NDIS Workforce Capability Framework so that the Core Capability 'Communicate Effectively' for Advanced Support Work explicitly includes the skills and understanding needed for working with interpreters.

Recommendation 6.3 Access to appropriately skilled and qualified interpreters

The Australian Government, the National Accreditation Authority for Translators and Interpreters (NAATI) and the National Disability Insurance Agency (NDIA) should take steps to ensure people with disability have access to appropriately skilled and qualified interpreters as needed.

Training for interpreters

NAATI should require interpreters to complete training in disability awareness before receiving accreditation and as part of their ongoing professional development to maintain accreditation.

Interpreters in disability service provision

The NDIA should:

- ensure staff are aware of the NDIA's Practice Guide on Accessible Communication and the provisions of the Practice Guide for Aboriginal and Torres Strait Islander planning support relating to interpreters and translation
- provide training for staff on how to arrange and work with an interpreter.

The Minister for the National Disability Insurance Scheme (NDIS), in consultation with states and territories, should:

- amend the *National Disability Insurance Scheme (Provider Registration and Practice Standards) Rules 2018* (Cth) to introduce a standard on effectively working with interpreters
- amend the *National Disability Insurance Scheme (Quality Indicators for NDIS Practice Standards) Guidelines 2018* (Cth) to include indicators relevant to the standard on working effectively with interpreters, including that providers have relevant policies and procedures in place.

The NDIS Quality and Safeguards Commission should amend the NDIS Workforce Capability Framework to provide that the Communicate Effectively Core Capability for Advanced Support Work explicitly includes working with interpreters.

Endnotes

- 1 Exhibit 5-31, 'Statement of Dr Ariella Meltzer', 7 August 2020, at [10].
- 2 Exhibit 5-31, 'Statement of Dr Ariella Meltzer', 7 August 2020, at [11–14].
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- 4 Australian Government Department of Social Services, Australia's Disability Strategy 2021–2031, December 2021, p 13.
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- 26 Committee on the Rights of Persons with Disabilities, *General comment no. 2, Article 9
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- 30 In early to mid-2019, the National Civil Society Convention on the Rights of Persons with Disability
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- 35 Ron McCallum, *The United Nations Convention on the Rights of Persons with Disabilities:
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2. Supported decision-making

Key points

- People have the right to make decisions, control their lives and exercise choice. However, for many people with disability, particularly people with cognitive disability, this right is limited.
- People with disability often have decisions made for them, even when they may not want these decisions made or agree with them. This can happen in everyday life or through formal systems such as guardianship and administration. This is known as **substitute decision-making**.
- People with disability under guardianship and administration may experience violence, abuse, neglect and exploitation. They may also face limits on their autonomy and a lack of cultural safety while under guardianship.
- **Supported decision-making** is another way to approach decision-making. It assists people with disability to make decisions that reflect their will and preferences. It recognises people with disability have the right to make decisions, but may need support to do so. It is key to enabling the autonomy of people with disability.
- Supported decision-making should be embedded in guardianship and administration law and practice to ensure substitute decision-making only happens as a last resort and in the least restrictive manner.
- Tribunal processes and laws need to be improved to assist people with disability to participate in hearings. Public disclosure and confidentiality provisions should also be strengthened.
- There must be greater investment in education about and capacity building around supported decision-making to increase community awareness and shift attitudes about the ability of people with disability to make decisions.
- People with disability need more opportunities to develop financial skills.
- Public trustees' fees and charges must have greater transparency and equity. A national approach to data collection and reporting is critical to ensuring long-term, successful reform.

2.1. Introduction

For far too long people with disability in Australia have been denied the right to make their own decisions with appropriate support. For far too long, people with disability have been denied the dignity of risk and the freedom to choose how they live their own lives with independence. Our society cannot be allowed to protect people with disability to the extent that they cannot choose to live their own lives as they wish and to experience the consequences of those choices.¹

The Royal Commission's terms of reference recognise the human rights of people with disability, including 'respect for their inherent dignity and individual autonomy'.² In this chapter, we discuss limits on the autonomy of people with disability. Autonomy can be understood as a person's right and freedom to make decisions, control their life, and exercise choice.³ In other words, autonomy is about a person living the life they want.

People with disability can be prevented from exercising autonomy and making decisions. One way this happens is through the guardianship and administration system, where others make decisions for people with disability.

Key to enabling the autonomy of people with disability is recognising that people with disability are able to make decisions and may sometimes need support to do so. Autonomy can be enhanced through supported decision-making.

In this chapter we examine ways to move away from an over reliance on guardianship and administration towards supported decision-making. We make a series of recommendations to increase the understanding and use of supported decision-making, designed to enable people with disability to exercise their autonomy.

Our inquiry

In Public hearing 30, 'Guardianship, substituted and supported decision-making', we examined people with disability's experience of decision-making and guardianship and administration systems. The evidence demonstrated guardianship and administration systems must be reformed to embed supported decision-making and include processes better aligned with human rights approaches.

We also commissioned a research report, *Diversity, dignity, equity and best practice: A framework for supported decision-making*,⁴ and held two policy roundtables on supported

decision-making and guardianship (held on 31 May and 1 June 2022).⁵ We considered submissions, responses to issues papers and private sessions.

In public hearings, we heard about how people with disability's day to day lives are affected when other people make decisions about:

- where they live
- how and when they spend money
- what medical treatment and medical procedures they will have
- legal matters such as making a will or contract
- when and how they can access supports and services.

We heard about the impact substitute decision-making can have on a person's life. It affects a person's freedoms; privacy; right to speak out about their experiences; and connection with family, friendship and community. For First Nations people, it also involves separation from culture and Country.⁶ We also heard how a person's decision-making skills develop, and how opportunities can arise when they are supported to make their own decisions.

By recounting evidence given by witnesses about their experiences we do not make any adverse findings against a particular person, government or organisation. Counsel Assisting explained this would be the case at Public hearing 30 by stating we would not be making 'adverse factual findings as to whether a particular person or government breached the law or breached a policy'.⁷

Issues relating to decision-making for people with disability have arisen across all of the Royal Commission's work. They are discussed in Volume 3, *Nature and extent of violence, abuse, neglect and exploitation*; Volume 4, *Realising the human rights of people with disability*; and Volume 10, *Disability Services*. Decision-making is also discussed in this volume, in Chapter 4, 'Health care and treatment' and Chapter 5, 'Reducing and eliminating restrictive practices'.

Our recommendations

A more inclusive society that recognises the human rights of people with disability requires a shift away from substitute decision-making towards supported decision-making.

Our recommendations in this chapter apply the rights in article 12 of the *Convention on the Rights of Persons with Disabilities (CRPD)*. They are intended to increase awareness and use of supported decision-making. This is through legal reform and shifts in policy and practice. Our recommendations will ensure the least restrictive approach is taken to uphold a person's right to autonomy.

In Volume 4 the Royal Commission recommends the enactment of a Disability Rights Act, which would include the right of people with disability to access and use supports in making and participating in decisions that affect them, communicating their will and preferences, and

developing their decision-making ability. The recommendations in this chapter complement our proposals in Volume 4.

We focus on guardianship and administration in this chapter. However, our recommendations have broader implications. We recognise there is a need for wide-ranging reform across different service systems, sectors and areas of law.⁸ Our recommendations are intended to be used as a model for further reform in all systems and areas of law that permit substitute decision-making.

Key concepts

Supported decision-making

supported decision-making is recognising adults' rights and people's rights to make decisions for themselves and trying to work out what kinds of supports do you build in to really stretch out the number of people who can make their own decisions or, at the very least, participate to the greatest extent possible.⁹

'Supported decision-making' is decision-making with the support of others. It starts from the premise that everyone is able to make decisions and should be supported to do so. The right to support for decision-making is recognised in article 12 of the *CRPD*.¹⁰

A wide range of practices can be used to assist people to make decisions and respect their will and preferences.¹¹ Supported decision-making can take different forms. It can be through:¹²

- support persons, peer support, advocacy, or assistance with communication so people can exercise their legal capacity for certain types of decisions. We explain legal capacity in Section 2.2
- universal design and accessibility measures, such as providing interpreters or information in an accessible format (see Chapter 1, 'Accessible information and communications')
- the development and recognition of diverse, non-conventional methods of communication, especially for people who use non-verbal forms of communication to express their will and preferences
- the ability to plan in advance – for example, a person can state their will and preferences when they are able to express them, and these should then be followed when they are not in a position to communicate their will and preferences.

The research report *Diversity, dignity, equity and best practice: A framework for supported decision-making* found that supported decision-making provides:¹³

- greater exercise of choice and control
- support to navigate complex systems
- assistance to understand information and explore a broad range of options
- increased opportunities to make decisions
- a greater likelihood that decisions would reflect the preferences of people with disability.

The researchers considered supported decision-making a fundamental strategy for putting rights into practice and safeguarding, empowering and furthering wellbeing of people with disability. They found it has benefits beyond the individual by promoting change in social attitudes towards people with disability and emphasising the importance of social connections.¹⁴

Substitute decision-making

‘Substitute decision-making’ is decision-making by someone on behalf of another person with disability. It takes place because the person with disability is considered to lack capacity to make decisions themselves. Substitute decisions can be made on to personal matters, financial, property and health matters.

Substitute decision-making can take place in informal situations or through formal arrangements under law. Informal substitute decision-making can happen in many areas of life. We have heard it can be a feature of daily life for people in closed settings, including group homes.¹⁵ In formal arrangements, someone other than the person with disability can appoint a substitute decision-maker. This can be done against their will.¹⁶

Substitute decision-making can significantly limit an adult’s autonomy and their ‘will and preferences’.¹⁷ It is usually justified because a person is said to lack decision-making capacity, and the substitute decision-making can protect their perceived ‘best interests’.

Substitute decision-making can affect all people with disability, but people with cognitive or psychosocial disability are disproportionately affected.¹⁸ Most of the evidence concerning substitute decision-making we received concerned people with cognitive disability.

Witnesses with lived experience of disability shared the types of substitute decisions they experienced. At Public hearing 3, ‘The experience of living in a group home for people with disability’, AAI described the many ways choices were made on behalf of her daughter, including when she could go to bed or her choice of tea or coffee.¹⁹ Ms Sarah Forbes, the Advocacy Manager at Victorian Advocacy League for Individuals with Disability (VALiD), told us about a couple who were prevented from being in a same-sex relationship because it was believed they lacked capacity to consent to the relationship.²⁰ At Public hearing 20, ‘Preventing and responding to violence, abuse, neglect and exploitation in disability services (two case studies)’, we heard that a service provider suggested ‘Sophie’s’ parents seek guardianship of her so they could take her phone away to stop her visiting internet dating sites.²¹

2.2. Human rights and autonomy

... people have the right to make their own decisions, and they should be supported to do so ...²²

The human rights of people with disability are an integral part of our inquiry.

Autonomy, supported decision-making and the *CRPD*

Article 12 of the *CRPD*

The preamble of the *CRPD* states the importance of autonomy for people with disability.²³ The first of the *CRPD*'s general principles in article 3 is 'Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons'.

Article 12 is the central provision on autonomy and decision-making. It reaffirms that people with disability have the right to recognition everywhere as persons before the law. It asserts that everyone has the right to make decisions about their life, regardless of cognitive ability, and should have the necessary support to do so.

In effect, supported decision-making is identified as a right of people with disability.²⁴ This is a significant human rights development for people with disability. It requires a shift away from substitute decision-making towards a system that enables decision-making authority to rest with the person with disability.

At Public hearing 31, 'Vision for an inclusive Australia', Mr Gerard Quinn, the United Nations Special Rapporteur on the rights of persons with disabilities, spoke about the importance of article 12. He said it is one of two 'bedrock' provisions in the *CRPD*. It aims to restore to people with disability 'power over their own lives, autonomous decision-making over their own lives, in as much as any of us have that capacity, and, therefore, to ground the entire Convention on a theory of personhood'.²⁵

Article 12 provides:

1. States Parties reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law.
2. States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.
3. States Parties shall take appropriate measures to provide access by persons with

disabilities to the support they may require in exercising their legal capacity.

4. States Parties shall ensure that all measures that relate to the exercise of legal capacity provide for appropriate and effective safeguards to prevent abuse in accordance with international human rights law. Such safeguards shall ensure that measures relating to the exercise of legal capacity respect the rights, will and preferences of the person, are free of conflict of interest and undue influence, are proportional and tailored to the person's circumstances, apply for the shortest time possible and are subject to regular review by a competent, independent and impartial authority or judicial body. The safeguards shall be proportional to the degree to which such measures affect the person's rights and interests.
5. Subject to the provisions of this article, States Parties shall take all appropriate and effective measures to ensure the equal right of persons with disabilities to own or inherit property, to control their own financial affairs and to have equal access to bank loans, mortgages and other forms of financial credit, and shall ensure that persons with disabilities are not arbitrarily deprived of their property.²⁶

Legal capacity

The Committee on the Right of Persons with Disabilities (CRPD Committee) explained that 'legal capacity' is the ability to hold rights and duties (legal standing) and to exercise those rights and duties (legal agency).²⁷ It is instrumental to legal personhood and allows a person's decisions and actions to be recognised and respected by the law. Article 12(3) of the *CRPD* emphasises that the provision of support is the first response to any compromise in decision-making ability.²⁸

Article 12(4) addresses the exercise of legal capacity. In a report prepared for the Royal Commission, *The United Nations Convention on the Rights of Persons with Disabilities: An Assessment of Australia's Level of Compliance*,²⁹ Emeritus Professor Ron McCallum AO said that article 12(4) 'is a complex paragraph which is somewhat unclear about when, if ever, legal capacity can be overridden'.³⁰ He said that the article 'does not directly state that all substituted decision-making mechanisms are prohibited, but requires safeguard mechanisms'.³¹ These safeguard mechanisms must respect the rights, will and preferences of people with disability.³²

The former United Nations Special Rapporteur on the rights of persons with disabilities, Ms Catalina Devandas, emphasised the safeguards referred to in article 12 are 'meant to protect individuals in the provision of support'. Safeguards should not prevent people from making decisions, taking risks and making mistakes.³³ This is also known as dignity of risk – that is, a person has the right to take reasonable risks.

We must avoid protectionism to the point of not allowing people with disability to take risks as any person would expect to do so in our society.³⁴

Mr Quinn has previously stated people with disability need to be given access to supported decision-making, given many people with disability may lack the natural ‘ancillary supports’ such as ‘social capacity’ that people without disability enjoy without even noticing it.³⁵

Interpretative declaration concerning article 12

When the Australian Government ratified the *CRPD*, it made an interpretative declaration concerning articles 12, 17, and 18, without purporting to exclude or modify their legal effects.³⁶

On article 12, the interpretative declaration states:

Australia recognises that persons with disability enjoy legal capacity on an equal basis with others in all aspects of life. Australia declares its understanding that the Convention allows for fully supported or substituted decision-making arrangements, which provide for decisions to be made on behalf of a person, only where such arrangements are necessary, as a last resort and subject to safeguards.³⁷

Later in this chapter we discuss different views and approaches to the interpretative declaration on article 12 (see Section 2.11).

Principled approach to supported decision-making

In Australia there is no uniform understanding of or approach to supported decision-making.³⁸ We adopt a principled approach to supported decision-making based on the research report, *Diversity, dignity, equity and best practice: A framework for supported decision-making*.³⁹

A principled approach centres decision-making on the will and preferences of people with disability. It contrasts with a ‘binary approach’, which distinguishes sharply between supported and substitute decision-making. Under the binary approach, there is either supported decision-making (where a person is supported to participate in a decision actively and retains control) or there is substitute decision-making (where a person cannot actively participate and a substitute decision is made by others based on the person’s perceived ‘best interests’).⁴⁰

According to the principled approach, some substitute decisions can be considered part of supported decision-making. This will depend on the nature of the decision and the context. Substitute decision-making based on a ‘will and preference’ approach can be considered part of supported decision-making, but substitute decision-making based on ‘best interests’ is inconsistent with the principled approach.⁴¹

Under a principled approach, a person is supported to maximise their autonomy in making decisions. Under this approach, a ‘representative’ decision-maker can be appointed as a last resort. Where this happens, a person’s will and preferences must remain central and be reflected in the representative’s decision. If a person cannot actively participate in decision-making or communicate their will and preferences, the representative makes decisions based on their best interpretation of the person’s will and preferences.⁴²

A principled approach allows for substitute decision-making, where a person’s will and preferences are overridden when necessary to prevent serious harm. In these very limited circumstances, a representative’s decision-making may be guided by the standard of promoting ‘personal and social wellbeing’.⁴³

We discuss the concepts of ‘will and preferences’ and ‘personal and social wellbeing’ further in Section 2.5.

Supported decision-making and people with disability in Australia

As at 2018, 2.4 million people under 65 in Australia lived with disability.⁴⁴ The 2018 Australian Bureau of Statistics *Survey of Disability, Ageing and Carers* data provides some insight into the profile of people with disability who may require supported decision-making. The Australian Bureau of Statistics defines disability as ‘any limitation, restriction or impairment which restricts everyday activities and has lasted, or is likely to last, for at least six months’.⁴⁵ Of the people aged 15 to 64 years with disability who responded to the question ‘whether needs assistance to make decisions or think through problems because of disability’,⁴⁶ the data showed:

- 19 per cent needed assistance to make decisions or think through problems⁴⁷
- people with disability aged 15 to 24 years were 2.4 times more likely to need assistance when making decisions, compared with those aged 25 to 64 years⁴⁸
- people with intellectual disability were 2.4 times more likely to need assistance than the general population with disability (47 per cent compared with 19 per cent)⁴⁹
- people with psychosocial disability were 2.4 times more likely to need assistance than the general population with disability (46 per cent compared with 19 per cent).⁵⁰

2.3. Substitute decision-making and guardianship

Australia has a range of laws and processes for substitute decision-making. Substitute decision-making occurs within various legal and service systems.

The main way that formal substitute decision-making occurs is through the laws governing guardianship and administration. We have focused our inquiry on the substitute decision-making for adults under guardianship and administration.

Substitute decision-making can also occur through Centrelink and National Disability Insurance Scheme (NDIS) nominees, default health substitute decision-makers such as ‘persons responsible’, and enduring attorneys and guardians.⁵¹

History of guardianship and substitute decision-making

In the past, many people with disability in Australia were denied the right to make decisions because a court or other body considered they lacked the capacity to make decisions.⁵²

Parens patriae jurisdiction

Judges of superior courts are empowered to make decisions for a person who lacks capacity in the exercise of what is known as the *parens patriae* (meaning ‘parent of the nation’) jurisdiction.⁵³ In principle, the court exercises this power with the aim of protecting people who are deemed to lack capacity from abuse and exploitation.⁵⁴

Historically, the powers held by the monarch, known as the royal prerogative, were vested in the Court of Chancery. The *parens patriae* jurisdiction derived from these powers.

Today, the jurisdiction is primarily concerned with the care and protection of children and people who are considered to lack the capacity to take care of themselves. The court can make orders for the protection of the person (relating to their body, or physical and personal needs), as well as for the person’s estate (property).

The *parens patriae* jurisdiction is broad and enables the court to respond to the individual needs and circumstances of people needing protection.⁵⁵ While the jurisdiction is broad, it is also exceptional. The power is:⁵⁶

generally to be exercised only in exceptional cases and with considerable caution. In the case of an adult, this caution is especially important because care should always be taken to ensure that there is no interference unlawfully in the free will of a capable individual.⁵⁷

In practice, courts usually exercise the *parens patriae* power in relation to children. The overriding consideration governing the exercise of the court’s power is the best interests of the child. Applying this criterion may involve a court overriding the wishes of the parents or even the child if doing so is considered necessary to protect the child from serious harm.⁵⁸ Perhaps surprisingly, courts have exercised this power to authorise irreversible sterilisation of a young woman living with an intellectual disability⁵⁹ and the termination of pregnancies of women with intellectual disability.⁶⁰

Development of guardianship and administration laws

Over time, each state and territory has transferred guardianship and administration decision-making authority exclusively from courts in the exercise of the *parens patriae* jurisdiction to

guardianship boards, and later to specialist divisions within administrative tribunals. In 1963 Tasmania enacted legislation, which established both a Guardianship Board, with power to regulate its own proceedings, and a Mental Health Review Tribunal.⁶¹ During the 1980s and 1990s, the other states and territories adopted a similar approach.⁶²

In 2019, Victoria passed landmark reforms to its guardianship system. As part of the reforms, new provisions allowed supporters in decision-making to be appointed as a less restrictive measure where possible.⁶³ These amendments provided a modern framework for appointing a guardian and/or administrator, and introduced statutory recognition for supported decision-making.⁶⁴ We discuss the Victorian legislation in more detail in the next section.

State and territory legal frameworks for guardianship and administration

Guardianship and administration orders

There is no national uniform guardianship and administration law in Australia. The formal appointment of guardians and administrators in Australia is governed by state and territory laws.⁶⁵ Broadly speaking, guardians and administrators are appointed through:

- orders of tribunals or courts appointing a guardian or person to manage personal matters or financial affairs of a person
- a formal instrument such as an enduring guardianship or enduring power of attorney.

Guardianship and administration orders are formal orders made by a court or tribunal authorising a person or organisation to make decisions for, act and give consent on another person's behalf.

Under a guardianship order, subject to the terms of the orders, a guardian may make decisions about:⁶⁶

- where a person lives
- what support services they receive
- health care matters
- the use of restrictive practices
- who they can have contact with
- day to day issues.

Under an administration order, an administrator is authorised to manage the financial affairs of another person – for example, by making legal decisions about financial matters and property.

Guardians and administrators are generally appointed when a tribunal or court has determined

a person does not have the 'capacity' to make a decision and a substitute decision-maker is needed to make that decision on their behalf.

With some exceptions, a guardian or administrator must act in the 'best interests' of the person rather than in conformity with the person's 'will and preferences'. Most states and territory legislation provides that guardianship and administration orders should only be made as a last resort and in the least restrictive manner.⁶⁷ A guardian or financial administrator may be:⁶⁸

- a partner
- a family member or friend of a person with disability
- or someone else who has a connection with the person.

We refer to this group as 'private guardians and administrators'.

A guardian or financial administrator may also be public advocates, public guardians and public trustees. We discuss their roles in the next section.

Role of public advocates, public guardians and public trustees

Under guardianship laws, public officials may be appointed as guardians or administrators, but only as a last resort.⁶⁹ Their titles, functions and powers vary between states and territories. The last-resort guardians have been designated as public advocates (in Victoria, South Australia and Western Australia) or public guardians (in New South Wales, Queensland, Tasmania and the Northern Territory).

In most states and territories, the administrator of last resort is referred to as the public trustee. However, in Victoria this position is called the State Trustees and in New South Wales it is the NSW Trustee and Guardian. In the Australian Capital Territory a single agency, the Public Trustee and Guardian, is both the guardian and administrator of last resort.⁷⁰

Public trustees' functions and powers are generally similar across states and territories. Public trustees have a fiduciary duty to people under administration orders. They must not act when there is a conflict of interest or to make a profit (except for charges authorised by law). In addition to managing the financial affairs of people with a disability, the public trustee can also prepare wills and powers of attorney, act as an executor for deceased estates and administer trusts.

The functions and powers of public guardians and public advocates differ. In New South Wales, Western Australia and the Northern Territory, for instance, the public guardian's functions are largely limited to making decisions on behalf of the person who is under a guardianship order. In other jurisdictions, however, the public advocate has broader responsibilities that include advocating for and safeguarding people with disability more generally. This may extend to:

- protecting them from abuse, neglect or exploitation
- acting on their behalf to obtain assistance

-
- encouraging the development of programs and services for their benefit.

Most states and territories have either a public guardian or public advocate. However, in addition to having a public guardian, Queensland and the Australian Capital Territory also have a separate public advocate statutory role. This role is limited to systemic advocacy functions. As we discuss in Chapter 3, 'Advocacy and informal supports', systemic advocacy involves working for long-term change to promote the rights and interests of people with disability.

In this *Final report*, we use the terms 'public guardian' and 'public trustee' to include equivalent positions across all states and territories.

Data on guardianship and administration

In this section, we provide a snapshot of the current state of guardianship and administration in Australia, highlighting differences and gaps in data reporting across states and territories.

We have drawn on data provided to the Royal Commission by New South Wales, Victoria, Queensland, Western Australia and Tasmania prepared for Public hearing 30. Public guardians and public trustees in each of those states were asked to provide data on the orders that appointed them. We asked them for information about:

- the number of people appointed as guardian or administrator
- the characteristics of people under those orders
- the duration of the orders.

For states and territories that were not the focus of Public hearing 30, we relied on data in annual reports, where available, as well as data from the Australian Guardianship and Administration Council (AGAC).⁷¹

Overall, there is a lack of consistent data on guardianship and administration in Australia. The type and extent of data guardianship lists or divisions of civil and administration tribunals publicly report on varies significantly. The variation is in part due to different reporting requirements in relevant legislation. Public guardians and public trustees also report on data in their annual reports, although the nature and amount of this data varies too. Our recommendation to improve data collection and reporting is in Section 2.9.

Applications and orders for administration or guardianship

The first year of AGAC's centralised reporting of new Australian adult guardianship orders was for 2017–18 financial year.⁷² Since then, AGAC has published data annually on the number of adult guardianship and administration applications, and new orders made by state and territory administrative tribunals. Drawing on AGAC annual reports from 2017–18 to 2021–22, the total number of guardianship and administration applications and orders increased from:⁷³

- 22,273 applications in 2017–18 to 25,252 in 2021–22. This represents a 13 per cent increase over five years.

- 16,537 orders made in 2017-18 to 19,879 in 2021–22. This represents a 20 per cent increase over the same period.

The numbers of applications and new orders recorded in AGAC's annual report for 2021–22, the latest reporting year publicly available, are set out in Table 6.2.1 (applications) and Tables 6.2.2, 6.2.3 and 6.2.4 (orders).⁷⁴ AGAC explained one reason there are many more applications than orders is that two applications for guardianship or administration can result in only one order. For example, this can happen where two applications are made – one for a short-term order and the other for a long-term order. In that case, the short-term order becomes a long-term order, which means there would be two applications but only one order.⁷⁵

Table 6.2.1: Guardianship and administration/financial management applications made between 1 July 2021 and 30 June 2022

State	Guardianship	Administration/ financial management	Total
ACT	190	180	370
NSW	4590	3,394	7,984
NT	NA	NA	236
QLD	2,495	2,535	5,030
SA	NA	NA	2,625
TAS	282	242	524
VIC	2,910	2,857	5,767
WA	NA	NA	2,716
Total	NA	NA	25,252

Note: South Australia, Western Australia and the Northern Territory case management systems do not enable separate totals of different application types to be provided. Victorian data draws on information provided by the Office of the Public Advocate.

Source: Australian Guardianship and Administration Council, *Australian adult guardianship orders 2021/22*, Annual report, 2022, p 1.

Table 6.2.2: Guardianship orders made between 1 July 2021 and 30 June 2022

State	Public orders	Private orders	Total
ACT	31	163	194
NSW	1,310	1,711	3,021
NT	78	100	178
QLD	673	696	1,369
SA	480	1,118	1,598
TAS	88	67	155
VIC	653	872	1,525
WA	710	1,294	2,004
Total	4,023	6,021	10,044

Note: Victorian data draws on information provided by the Office of the Public Advocate.

Where appropriate data is available, orders are categorised as 'public orders' where the public guardian or public trustee is appointed; other appointments are categorised as private orders.

Source: Australian Guardianship and Administration Council, *Australian adult guardianship orders 2021/22*, Annual report, 2022, p 1.

Table 6.2.3: Administration/financial management orders made between 1 July 2021 and 30 June 2022

State	Public orders	Private orders	Total
ACT	36	148	184
NSW	1,095	1,351	2,446
NT	87	91	178
QLD	720	1,110	1,830
SA	376	692	1,068
TAS	78	106	184
VIC	530	1,630	2,160
WA	712	1,073	1,785
Total	3,634	6,201	9,835

Note: Victorian data draws on information provided by the Office of the Public Advocate.

Where appropriate data is available, orders are categorised as 'public orders' where the public guardian or public trustee is appointed; other appointments are categorised as private orders.

Source: Australian Guardianship and Administration Council, *Australian adult guardianship orders 2021/22*, Annual report, 2022, p 1.

Table 6.2.4: Total guardianship and administration/financial management orders made between 1 July 2021 and 30 June 2022

State	Total guardianship and administration/ financial management orders
ACT	378
NSW	5,467
NT	356
QLD	3,199
SA	2,666
TAS	339
VIC	3,685
WA	3,789
Total	19,879

Note: Victorian data draws on information provided by the Office of the Public Advocate.

Where appropriate data is available, orders are categorised as 'public orders' where the public guardian or public trustee is appointed; other appointments are categorised as private orders.

Source: Australian Guardianship and Administration Council, *Australian adult guardianship orders 2021/22*, Annual report, 2022, p 1.

Between 2017 and 2022, the average annual growth rate in numbers of people subject to new guardianship and administration/financial management orders increased an average of 4.8 per cent across Australia as a whole. Across states and territories new guardianship and administration/financial management orders:

- increased an average of 9.2 per cent per year in the Australian Capital Territory
- increased an average of 8.3 per cent per year in New South Wales
- increased an average of 16 per cent per year in Northern Territory⁷⁶

- decreased an average of 3.1 per cent per year in Queensland
- increased an average of 11.6 per cent per year in South Australia
- decreased an average of 8 per cent per year in Tasmania
- increased an average of 0.6 per cent per year in Victoria
- increased an average of 11.9 per cent per year in Western Australia.

Figure 6.2.1 shows the combined total number of people subject to new guardianship and administration/financial management orders in each jurisdiction and over the past five financial years (2017–22). This only reflects new orders as there is insufficient data to compare the number of new orders to overall orders.

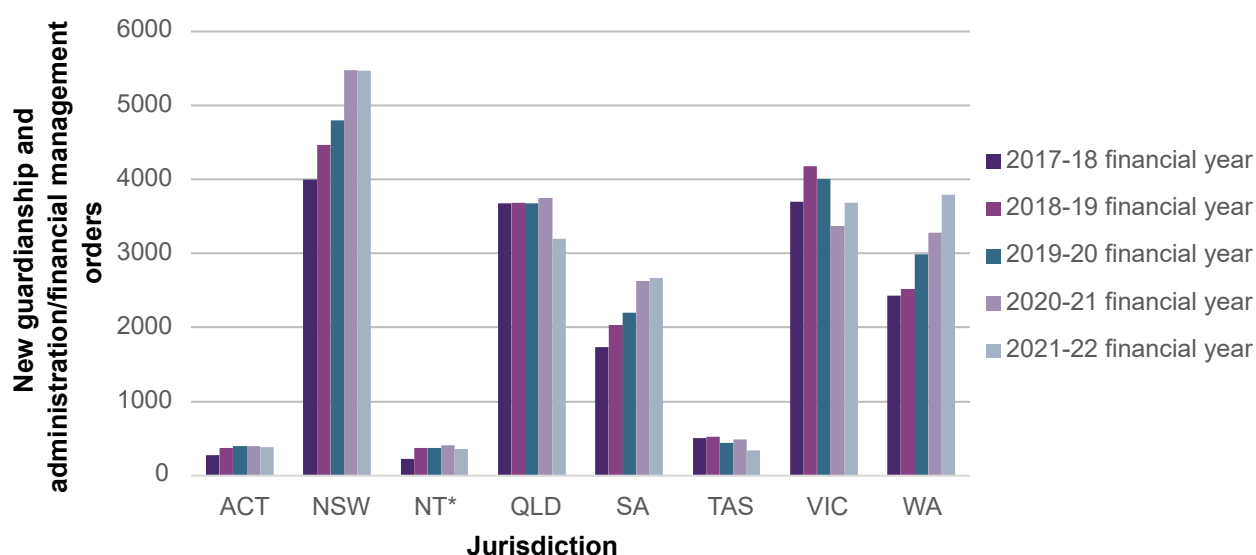


Figure 6.2.1: Number of people subject to new guardianship and administration/financial management orders in each jurisdiction between 2017 and 2022

Note: For the Northern Territory, data is only available from 1 December 2017. For all other jurisdiction data starts from 1 July 2017.

Source: Australian Guardianship and Administration Council, *Australian Adult Guardianship Orders 2017/18*, Annual report, January 2019; Australian Guardianship and Administration Council, *Australian Adult Guardianship Orders 2018/19*, Annual report; Australian Guardianship and Administration Council, *Australian Adult Guardianship Orders 2019/20*, Annual report; Australian Guardianship and Administration Council, *Australian Adult Guardianship Orders 2020/21*, 2022.

In Tables 6.2.2, 6.2.3 and 6.2.5, public guardian or public trustee appointments are categorised as ‘public orders’. Other appointments are categorised as ‘private orders’. Aside from the data they provide to the AGAC for publication in its annual reports, tribunals generally do not report on the number of public as opposed to private appointments. Some public guardians and public trustees publish information in their annual reports on public appointments.

Table 6.2.5 shows the total number of appointments of public guardians and public trustees.⁷⁷ It does not represent the true extent of guardianship and administration orders across states and territories because it does not include appointments of private guardians or administrators. However, these figures, together with data from tribunals, give a sense of the number of people affected by guardianship and administration. They also show a much higher number of people have their financial affairs administered by public trustees than have guardianship decision-making by public guardians.

Table 6.2.5: Total number of appointments of the public guardian and public trustee in October and November 2022

State	Public guardian	Public trustee
NSW	3,726 ^a	12,580 ^b
VIC	1,046 ^c	9,252 ^c
QLD	3,565 ^d	9,635 ^e
WA	3,213 ^f	5,390 ^g
SA	1,675 ^h	NA
TAS	308 ⁱ	1249 ^j
ACT	216 ^k	495 ^k
NT	670 ^l	NA

Note: New South Wales, Victoria, Queensland, Western Australia and Tasmania provided data under notice for Public hearing 30 that was up to date in October and November 2022. The figures for South Australia, the Australian Capital Territory and the Northern Territory has been drawn from relevant annual reports of the public guardian and public trustee where available between 2021 and 2022.

‘NA’ Indicates there is no publicly available data.

^a As at 31 October 2022. Exhibit 30-136, ‘Statement of Megan Osborne’, 14 November 2022, at [24].

^b As at 31 October 2022. Exhibit 30-121, ‘Statement of Caroline Cuddihy’, 14 November 2022, at [32–34].

^c As at 20 October 2022. Exhibit 30-099, ‘Statement of Colleen Pearce’, 5 November 2022, at [38].

^d As at 27 October 2022. Exhibit 30-053, ‘Statement of Shayna Smith’, 11 November 2022, at [27].

^e As at 10 November 2022. Exhibit 30-052, ‘Statement of Samay Zhouand’, 10 November 2022, at [21].

^f The Public Advocate acts as a statutory appointee for both guardianship and administration orders. As at 24 October 2022, Exhibit 30-008, 'Statement of Pauline Bagdonavicius', 4 November 2022, at [38].

^g Public Trustee (WA), *Annual report 2021–22*, September 2022, p 13.

^h Office of the Public Advocate (SA), *Annual report 2021–22*, September 2022, p 10.

ⁱ As at 28 October 2022. Exhibit 30-201, 'Statement of Angela McCrossen', 8 November 2022, at [5].

^j As at 28 October 2022. Exhibit 30-205, 'Statement of Todd Kennedy', 11 November 2022, at [4].

^k Public Trustee and Guardian (Australian Capital Territory), *Annual report 2021/22*, July 2022, at [18].

^l This includes where the Public Guardian was appointed sole or joint guardian, which includes where the Public Guardian is appointed with private guardians. This may also include Public Trustee for financial management. Northern Territory Public Guardian and Trustee, *Annual report 2021–22*, September 2022, p 31.

We provide more detail on guardianship and administration applications and orders across jurisdictions in Appendix 6A.

Duration of orders

There is limited available data on the duration of guardianship and administration orders across the states and territories. We have compiled available data on the number of orders appointing the public guardian or public trustee that were revoked in the year 2021–22 (see Table 6.2.6).

Table 6.2.6: Number of guardianship and administration orders revoked where the public guardian or public trustee was appointed in 2021–22

State	Guardianship orders revoked	Administration orders revoked
NSW	58 ^a	473 ^b
VIC	408 ^c	270 ^d
QLD	363 ^e	166 ^f
WA	145 ^g	NA
SA	55 ^h	NA
TAS	38 ⁱ	32 ^j
ACT	NA	NA
NT	NA	NA

Note: New South Wales, Victoria, Queensland, Western Australia and Tasmania provided data under notice for Public hearing 30 that was up to date in October and November 2022.

'NA' Indicates there is no publicly available data.

^a Exhibit 30-136, 'Statement of Megan Osborne', 14 November 2022, at [38].

^b Exhibit 30-121, 'Statement of Caroline Cuddihy', 14 November 2022, at [47].

^c Exhibit 30-099, 'Statement of Colleen Pearce', 5 November 2022, at [49]. This paragraph notes that 'of these, 80 were time-limited orders that came to an end without a reassessment hearing being required.'

^d Exhibit 30-081, 'Statement of John Velegrinis', 8 November 2022, at [5.1]. This paragraph notes that of these, 'the client ceased to be subject to an administration order in 104 cases (of which, in 30 cases the client had been on the FIP [Financial Independence Program]); and (b) a different administrator was appointed in 166 cases'.

^e Exhibit 30-053, 'Statement of Shayna Smith', 11 November 2022, at [39].

^f Exhibit 30-052, 'Statement of Samay Zhouand', 10 November 2022, at [42]. This paragraph notes that 'of these, the Public Trustee was replaced by a new administrator in 56 appointment orders'.

^g Exhibit 30-008, 'Statement of Pauline Bagdonavicius', 4 November 2022, at [58].

^h Office of the Public Advocate (SA), *Annual report 2021–22*, p 16.

ⁱ Exhibit 30-201, 'Statement of Angela McCrossen' 8 November 2022, at [6]. This paragraph notes that 'this does not include orders that were lapsed'.

^j Exhibit 30-205, 'Statement of Todd Kennedy', 11 November 2022, p 6.

Profile of people under guardianship and administration orders

There is limited reported data on the profile of all people subject to guardianship and administration applications and orders. There is more information on represented people under orders appointing the public guardian or public trustee, particularly on disability types, age and cultural background among represented people. The extent of this data varies across jurisdictions. Also, considerably less information is reported about people under orders appointing the public trustee, than people who are under orders appointing a public guardian.

We have provided an overview of the available data on the characteristics of people under guardianship and administration orders across jurisdictions below. More detail is provided in Appendix 6A.

Types of impairment represented among people under orders

The data on types of impairment is not uniform. Some public guardians and public trustees categorised disability as 'psychiatric', 'intellectual', 'neurological', 'age related/dementia', 'brain injury', 'physical', and 'other'. Others provided more detail. Guardians and trustees categorise disability types differently. For example, the Victorian State Trustees record Huntington's disease as 'Dementia/Alzheimer's', whereas the Queensland Public Trustee records Huntington's disease as 'Neurological'. In some states and territories, the data on types or impairment is limited to the primary disability type. Others record all disability types where the person has more than one disability.

While the types of impairment reported were not uniform, the tables in Appendix 6A show people with psychological disability or cognitive disability, including dementia and intellectual disability, are over-represented among people under orders. While this data includes people of all ages, there is a much higher number of people with intellectual or psychosocial disability under orders than people with dementia or aged related disability.

We discuss data quality and inconsistency of data collected and reported further in Volume 12, *Beyond the Royal Commission*.

Age of people under orders

Most state and territory tribunals do not report how old a person was when a guardianship or administration order was made.⁷⁸ However, there is some information on the ages of people who are under orders appointing a public guardian or public trustee. Where available, this data is compiled Appendix 6A. This data shows that most public guardian and public trustee appointments are for people under 65 years.

First Nations and cultural representation of people under orders

Available data also shows that a higher number of First Nations people are under guardianship or administration orders appointing the public guardian or public trustee (see Tables 6.2.7 and 6.2.8). We discuss evidence on First Nations people under guardianship and administration later in the chapter.

Table 6.2.7: Number of people who identify as First Nations appointed the public guardian at June to November 2022

State	Number of First Nations people represented	Percentage of people represented who are First Nations
NSW	329 ^a	8.8%
VIC	46 ^b	4.4%
QLD	571 ^c	16.1% ^d
WA	570 ^e	18.3%
SA	NA	10.7% ^f
TAS	6 ^g	1.9%
ACT	15 ^h	NA
NT	NA	NA

Note: New South Wales, Victoria, Queensland, Western Australia and Tasmania provided data under notice for Public hearing 30 that was up to date in October and November 2022.

‘NA’ Indicates there is no publicly available data.

^a As at 31 October 2022. Exhibit 30-136, ‘Statement of Megan Osborne’, 14 November 2022, at [31].

^b As at 20 October 2022. Exhibit 30-211, OPA.9999.0012.0001, p 2.

^c As at 27 October 2022. Exhibit 30-053, 'Statement of Shayna Smith', 11 November 2022, at [35].

^d Note this share has been calculated using the denominator of 3,115 public guardianships appointed (which is current as of June 30, 2022).

^e As at 30 June 2022. Exhibit 30-008, 'Statement of Pauline Bagdonavicius', 4 November 2022, at [50]. The Public Advocate was guardian for 3,115 people at 30 June 2022.

^f Office of the Public Advocate (SA), *Annual report 2021–22*, p 10.

^g Exhibit 30-201, 'Statement of Angela McCrossen', 8 November 2022, at [5].

^h Australian Capital Territory Public Trustee and Guardian, *Annual report 2021–22*, p 44.

Table 6.2.8: Number of people who identify as First Nations appointed the public trustee at June to November 2022

State	Number of First Nations people represented	Percentage of people represented who are First Nations
NSW	920 ^a	7.3%
VIC	112 ^b	1.2%
QLD	829 ^c	8.6%
WA	NA	NA
SA	NA	NA
TAS	NA	NA
ACT	10 ^d	NA
NT	NA	NA

Note: New South Wales, Victoria, Queensland, Western Australia and Tasmania provided data under notice for Public hearing 30 that was up to date in October and November 2022.

'NA' Indicates there is no publicly available data.

^a As at 31 October 2022. Exhibit 30-121, 'Statement of Caroline Cuddihy', 14 November 2022, at [39], [42].

^b As at 20 October 2022. Exhibit 30-081, 'Statement of John Velegrinis', 8 November 2022, at [4.8].

^c As at 27 October 2022. Exhibit 30-052, 'Statement of Samay Zhouand', 10 November 2022, at [30].

^d Australian Capital Territory Public Trustee and Guardian, *Annual report 2021–22*, p 44.

Public guardians and public trustees in New South Wales, Victoria, Queensland, Tasmania and Western Australia were also asked for details of people under guardianship and administration orders from culturally and linguistically diverse backgrounds. No satisfactory records were kept in this regard. Some officeholders kept records of country of birth,⁷⁹ while others kept records of primary language spoken.⁸⁰

NDIS participation

Available data shows that most people with a public guardian appointed are also NDIS participants (see Table 6.2.9).

Table 6.2.9: Number and percentage of people who are NDIS participants and appointed the public guardian at June to November 2022

State	Number of people represented who are NDIS participants	Percentage of people represented who are NDIS participants
NSW	2,009 ^a	53.9% ^a
VIC	527 ^b	50.4%
QLD	2,634 ^c	73.9%
WA	2,050 ^d	65.8% ^e
SA	1,070 ^f	63% ^g
TAS	202 ^h	65.6%
ACT	NA	NA
NT ⁱ	NA	NA

Note: New South Wales, Victoria, Queensland, Western Australia and Tasmania provided data under notice for Public hearing 30 that was up to date in October and November 2022. The figures for South Australia and the Northern Territory have been drawn from relevant annual reports of the public guardian and public trustee where available between 2021 and 2022.

'NA' Indicates there is no publicly available data.

^a As at 31 October 2022. Exhibit 30-136, 'Statement of Megan Osborne', 14 November 2022, at [34].

^b As at 20 October 2022. Exhibit 30-099, 'Statement of Colleen Pearce', 5 November 2022, at [48].

^c As at 27 October 2022. Exhibit 30-053, 'Statement of Shayna Smith', 11 November 2022, at [37].

^d As at 30 June 2022. Exhibit 30-008, 'Statement of Pauline Bagdonavicius', 4 November 2022, at [57].

^e As at 30 June 2022. Exhibit 30-008, 'Statement of Pauline Bagdonavicius', 4 November 2022, at [57]. This paragraph states: 'Data as at 30 June 2022, indicates that 2,050 of the 3,115 adults for whom the Public Advocate was guardian also had NDIS involvement (that is, had an NDIA identifier number). Additionally, of the 3,115 adults for whom the Public Advocate was guardian, 1,973 were 65 years or younger, and of those adults, 94 per cent had NDIS involvement. Note, the denominator used for calculating the percentage was 3,115 (and not 3,213 mentioned in Table 6.2.4) as this number is also as of June 30, 2022.'

^f Office of the Public Advocate (South Australia), *Annual report 2021–22*, p 32.

^g Office of the Public Advocate (South Australia), *Annual report 2021–22*, p 32. Note the share used here reflects the percentage given in the annual report as it reflects the correct reference period

(as of June 2022) and not calculated using the South Australian total (1,675) in table.

^h Exhibit 30-201, 'Statement of Angela McCrossen' 8 November 2022, at [6].

ⁱ Indicates the Northern Territory data does not separate guardianship and administration type orders and only reports in relation to represented persons who are eligible for the NDIS.

Available data shows that most people with a public trustee appointed are also NDIS participants (Table 6.2.10).

Table 6.2.10: Number and percentage of people who are NDIS participants and appointed the public trustee at June to November 2022

State	Number of people represented who are NDIS participants	Percentage of people represented who are NDIS participants
NSW	5,535 ^a	44% ^b
VIC	4,319 ^c	46.7%
QLD	6,124 ^d	63.6%
WA	NA	NA
SA	NA	NA
TAS	NA	NA
ACT	NA	NA
NT ^e	NA	NA

Note: New South Wales, Victoria, Queensland, Western Australia and Tasmania provided data under notice for Public hearing 30 that was up to date in October and November 2022. The figures for South Australia, and the Northern Territory have been drawn from relevant annual reports of the public guardian and public trustee where available between 2021 and 2022.

'NA' Indicates there is no publicly available data.

^a As at 31 October 2022. Exhibit 30-121, 'Statement of Caroline Cuddihy', 14 November 2022, at [42].

^b As at 31 October 2022. Exhibit 30-121, 'Statement of Caroline Cuddihy', 14 November 2022, at [42]; Exhibit 30-121, 'Statement of Caroline Cuddihy', 14 November 2022, at [43], notes that NSW Trustee and Guardian does not typically interact with the NDIS on behalf of financial management clients in regard to the functions or services included in their NDIS package, except where it concerns customer transport. NSW Trustee provides information to the NDIS regarding the financial circumstances of financial management clients, to assist in development of their NDIS packages. The majority of NDIS interactions for financial management clients require advocacy and interventions outside of the legislated scope of powers for NSW Trustee and Guardian. As such, the data may be underrepresented'.

^c As at 20 October 2022. Exhibit 30-081, 'Statement of John Velegrinis', 8 November 2022, at [4.10].

^d As at 27 October 2022. Exhibit 30-052, 'Statement of Samay Zhouand', 10 November 2022, at [34], states, 'Currently, 6,353 of the Public Trustee's customers are recorded as being eligible to participate in the NDIS. 6,124 of those customers have a NDIS registration number recorded. 5,134 customers have a NDIS plan held on file.'

^e Indicates the Northern Territory data does not separate guardianship and administration type orders and only reports in relation to represented persons who are eligible for the NDIS.

Impact of the NDIS

... it appears that the NDIS systems and processes, and the changed relationship between service providers and people with disability in a market-based system, have had the unintended consequence of increasing the use of guardianship.⁸¹

Evidence from public guardians and public advocates from New South Wales, Victoria, Queensland and Western Australia indicates that the rollout of the NDIS has increased the number of people under guardianship and administration.

According to the Victorian Public Advocate, Dr Colleen Pearce, data that her office has collected over the past 14 years suggests there is an association between the NDIS and an increase in guardianship orders.⁸² The Victorian Office of the Public Advocate's (OPA) data showed:

- an increase in appointments of the OPA as a guardian for people with disability under the age of 65 years since 2013, when the first NDIS trial commenced in Victoria. By comparison, the numbers of appointments for people over 65 years of age remained relatively consistent, and even trended downward⁸³
- an increase in guardianship orders that include power to make decisions about services for people under 65 years, from 66 to 70 per cent before 2018-2019 up to 80 to 90 per cent in 2019-20⁸⁴
- an increase in the average length of time the Public Advocate was guardian for people under 65 years from 24 months in 2009-10 to 30 months in 2019-20. Guardianship orders were not getting longer, on average, for people over the age of 65 years⁸⁵
- upward trends in the number of people with intellectual disability or psychiatric illness under the Public Advocate's guardianship since the NDIS rollout.⁸⁶ While these trends already existed, they became more pronounced with the NDIS rollout.

The NSW Public Guardian's data showed, between 2018 and 2022, guardianship applications indicating the NDIS as the primary reason for applications increased by 367 per cent. The then NSW Public Guardian, Ms Megan Osborne, described this as 'staggering'.⁸⁷ In the same period, the proportion of applications indicating NDIS involvement went from 5 per cent to 22 per cent.⁸⁸

The NSW Trustee and Guardian data showed that for 2021–22, 748 out of 4,047 guardianship applications indicated the NDIS as the primary reason the application was made.⁸⁹ In the same period, 8,176 decisions were made about a represented person's participation in the NDIS, an 83 per cent increase on 2018–19.⁹⁰

The Queensland Public Guardian, Ms Shayna Smith, said the rollout of the NDIS has had a 'huge impact' on the Queensland Office of the Public Guardian. The number of people coming under public guardianship has increased and the nature of the work has changed.⁹¹

The Public Advocate in Western Australia, Ms Pauline Bagdonavicius, also observed that historically, the highest number of orders appointing the Public Advocate were related to treatment decisions. Now, the highest number of orders appointing the Public Advocate concern decisions about services. She said this appeared to be directly related to the NDIS and the need for the person with disability to give consent to services, service agreements and plans.⁹²

Administrative requirements

Public Advocate Dr Colleen Pearce expressed the Victorian OPA's ongoing concern that the administrative requirements of the NDIS were increasing guardianship applications.⁹³ These administrative requirements include filling in and signing forms. In a submission to the National Disability Insurance Agency (NDIA) on the development of a supported decision-making policy for the NDIS, the Victorian OPA stated:

An over-reliance on substitute decision-makers is particularly evident where support is needed for NDIS participants to complete administrative requirements of the NDIS access and planning process. OPA is concerned that, in an increasing number of cases, the NDIA is requesting guardianship appointments for the sole purpose of enabling participants to complete the administrative requirements to enter the scheme and complete planning.⁹⁴

Witnesses from the NDIA gave evidence at Public hearing 30. Mr Scott McNaughton, General Manager, National Delivery and Dr Sam Bennett, General Manager, Policy, Research and Advice, said the NDIA was unaware of the systemic issues described by the Victorian OPA, but they were willing to investigate.⁹⁵

Mr McNaughton and Dr Bennett said under the *National Disability Insurance Scheme Act 2013* (Cth) (*NDIS Act*) or *National Disability Insurance Scheme (Nominees) Rules 2013* (Cth) there was no legislative requirement for a participant or prospective participant to physically sign administrative forms.⁹⁶ They identified alternative ways of fulfilling the administrative requirements of the NDIS, including applying to the NDIA verbally or online and using an electronic signature on forms.⁹⁷

Obtaining consent for services

Dr Pearce told us some service providers require NDIS participants to enter contracts for services. In these circumstances, participants may require guardians to act on their behalf:

In our experience, even though service agreements are not legally required for the provision or receipt of most types of NDIS supports, service providers may refuse to provide services or threaten to walk away when they do not have a contractual arrangement of some form.⁹⁸

Ms Osborne said a guardian's consent to services where capacity may be questioned gives service providers a level of assurance.⁹⁹

Ms Bagdonavicius said that:

Due to the nature of the NDIS, a substitute decision-maker is likely to be required on an ongoing basis, to consent to services, and will therefore create a barrier for the revocation of guardianship orders for these people.¹⁰⁰

Navigating NDIS complexity

Witnesses also said the complexity of the NDIS has led to an increased reliance on guardianship, particularly to fill gaps in advocacy and support coordination services.¹⁰¹

Dr Pearce stated the dismantling of state-funded disability services and the commencement of the NDIS created gaps in the services available for people with disability to identify, manage and coordinate their services.¹⁰² As a result, guardians have assumed a service coordination role.¹⁰³ This is a role state-funded disability care managers previously performed.¹⁰⁴

Ms Bagdonavicius described how NDIS complexity led to increased guardianship applications for people with mental illness and intellectual disability:¹⁰⁵

prior to the introduction of the NDIS, the person themselves was able to navigate the disability services system and funding arrangements and/or the services and funding within the mental health sector, but they are now unable to navigate the system without assistance.

It also includes situations where family members or other parties who have traditionally assisted the person to navigate these systems are overwhelmed themselves by the complexity of the system, and therefore seek to have a substitute decision-maker appointed with the authority to make decisions regarding services.¹⁰⁶

Similarly, Ms Smith said guardians are required to support NDIS participant clients through complex planning and review processes.¹⁰⁷ They are also required to:

repeat the decision-making and other activities to support these processes numerous times during the period of the guardianship appointment in accordance with the NDIS planning cycles, as well as respond to changes to service providers and issues relating to the provision or quality of supports to clients by service providers. This complex and ongoing process prevents the revocation of guardianship appointments for most NDIS participants, which represent the majority of the Public Guardian's clients.¹⁰⁸

Experiences of guardianship and administration

Witnesses at Public hearing 30 told us about their experiences of guardianship and administration, which highlight the need for improvements to the way these systems operate in Australia.

Applications and tribunal processes

We heard people can make applications for guardianship and administration for a person with disability they do not know well and without proper consultation. For example, witnesses said applications may be made by social workers employed by hospitals and employees of disability service providers, with little if any communication with the person with disability or their family.¹⁰⁹

At Public hearing 30, Ms Julie Bury, who was diagnosed with Parkinson's disease at the age of 45 and has since sadly passed away, gave evidence.¹¹⁰ When she was in hospital for medical treatment, Ms Bury and her family met with medical staff and a social worker.¹¹¹ Ms Bury felt everyone at the meeting was making decisions for her. This included her son, who wanted her move into a nursing home.¹¹² Ms Bury did not know until about three months later, that a social worker had applied for an administration order seeking the appointment of the Queensland Public Trustee to manage her finances.¹¹³ She found out about the appointment when she discovered she could not withdraw money to pay a phone bill. The bank teller said her account had been 'seized by the Public Trustee'.¹¹⁴

Mr Uli Cartwright, a young person with intellectual disability, also described his experience of an application for an administration order. Mr Cartwright stated:

To this day, I don't know why [the support worker] made the application [for my administration order]. There were no problems with my finances, my rent and bills were paid. I recall staff frequently disagreed with my spending decisions, but I don't think that's a good enough reason to take away my rights. I don't remember being told about the application being made.¹¹⁵

Applications for guardianship or administration are sometimes made without fully exploring options for supported decision-making options.¹¹⁶ For example, at Public hearing 30, the Namok family gave evidence about the experience of Mr Simeon Namok, a Torres Strait Islander man with cognitive disability. Ms Bakoi Namok, Simeon's mother, said nobody explored the possibility that Simeon's family, rather than a guardian, could act as decision-making supporters. Ms Namok tried to explain to medical practitioners and social workers that culturally, guardianship was

not necessary, because she was able to speak for her family.¹¹⁷ Mr Cartwright also told us the support worker who applied for his administration order did not encourage him to meet with a financial counsellor first.¹¹⁸

People with disability and their families can also find it difficult to understand guardianship and administration processes.¹¹⁹ Ms Namok said the guardianship process was not explained to her before or during her tribunal hearing and she found it difficult to understand.¹²⁰ ‘Anthony’ told us when he heard an application had been made for his mother, ‘Killara’, he did not know about the State Administrative Tribunal in Western Australia and what was involved in guardianship.¹²¹ He also did not understand he could take on the role of a guardian.¹²²

When an application reaches a tribunal hearing, people with disability and their families are not always able to participate fully or even at all. Mr Cartwright told us he did not attend the hearing for his administration order and did not recall ever being told about it.¹²³ Ms Namok said she found it hard to follow what was discussed at her hearing. She felt she needed an interpreter or someone who could explain the proceedings to her, but the Queensland Civil and Administrative Tribunal (QCAT) did not offer an Aboriginal liaison officer. Ms Namok also said it was important in her culture to discuss things in person, but her hearing took place by telephone.¹²⁴

Several witnesses told us they did not have a legal representative to during the tribunal proceedings.¹²⁵ Mr Cartwright said:

I was never given the opportunity to have my voice heard. I didn’t have support to represent my interests and decisions were made for me by others who supposedly knew what was best for me without so much as hearing my voice. I did not lack the skills to articulate and express my own views - instead, in the whole process I was silenced.¹²⁶

Ms Matilda Alexander from Queensland Advocacy for Inclusion told us the majority of people facing guardianship and administration proceedings are not represented by a lawyer and usually do not have a lay advocate or qualified support person.¹²⁷

Experiences while under orders

Violence, abuse, neglect and exploitation

At Public hearing 30, we heard about some circumstances where guardians or administrators had neglected the interests of the person under orders, leading to adverse consequences for their health and safety.

We heard evidence about Killara’s experience of being under guardianship and administration orders that resulted in the Public Advocate and Public Trustee being appointed. The Public Advocate was appointed to make certain decisions, including accommodation decisions, on Killara’s behalf. At Public hearing 30, Killara’s son Anthony said he had no say in the Public Advocate’s decision to move Killara into a residential facility, was not consulted on where Killara was going to live and where he thought she would like to live.¹²⁸

The facility was old and reminded Killara of the government institutions she grew up in. Anthony recalled Killara telling him on every occasion he visited her, 'I'm scared. I hate it here'.¹²⁹ He said Killara described living in the facility in this way:

Well, she definitely told me every single time I seen her, 'I'm scared. I hate it here.' She felt worthless, hopeless; the whole lot. She had no purpose in life, by the looks of it. She had no future set up. She had – medical-wise, she couldn't even respond. You know, literacy and numeracy isn't mum's best, but she would know if there is something wrong and she tried to express it, and that's how she expressed it to me, is that, 'I don't like living here. I'm getting abused.' Etcetera.¹³⁰

Killara and Anthony told us they made several requests for Killara to leave the facility.¹³¹ Anthony said it was difficult to get hold of the Public Advocate.¹³²

Living in the facility also affected Killara's health and physical wellbeing. Anthony said, 'Every time I would see my mother at that facility, that's when I noticed there was massive signs of neglect.'¹³³ He told us about an untreated hepatitis C infection which led Killara to have Cirrhosis of the liver. While she was living in the facility, she also had untreated diabetes and eyesight issues and a lack of support with personal hygiene.

Anthony also described dental issues Killara had while she was living in the facility, and the treatment needed to address them:

I was sitting there over the dental chair to support my mum – my mother emotionally. She's had, [on] one occasion, eight teeth removed one day. The next day, healing, seven teeth. She's got dentures now.¹³⁴

Anthony told us when he complained about Killara's care, he was told this was the responsibility of the Facility and her healthcare providers.¹³⁵

At Public hearing 30, Counsel Assisting explained that the Royal Commission would not be making 'particular adverse factual findings as to whether a particular person or government breached the law or breached a policy' for this hearing.¹³⁶ We have recorded the evidence given by Anthony and Killara, but we do not make specific adverse findings about the Public Advocate or the Public Trustee about Killara's experiences or treatment.

At Public hearing 30 we also heard evidence about 'Howie' and his health care while he was under a guardianship order. Howie is a man with intellectual disability. Howie said he experienced very poor dental health while under the guardianship of the Public Guardian. This did not improve until his sister Austyn took over as his guardian.¹³⁷

We also heard about financial mismanagement and conflicts of interest, involving fees and decisions about financial matters.¹³⁸ We discuss this further in Section 2.8.

We were told about situations where family members were appointed as guardians and were able to address neglect experienced by their family members with disability. Anthony told us

once he was appointed guardian for medical treatment decisions for his mother, he was able to address a number of significant health issues Killara had. These included untreated diabetes and a hepatitis C infection that went untreated while she was under a guardianship order appointing the Public Advocate. Anthony was also able to ensure Killara's health was being reviewed by a culturally appropriate health service. This had not previously occurred.¹³⁹ She was fitted for dentures and can now smile.¹⁴⁰

Similarly, Austyn described how she was able to address concerns about the care from Howie's service provider.¹⁴¹ Austyn also has tried to arrange services and activities for Howie that he enjoys.¹⁴²

Limits on autonomy

People under guardianship and administration can experience restrictions on their autonomy and can be denied the dignity of risk.

Mr Cartwright and Mr John O'Donnell said they were prevented from making spending decisions that a person in their 20s without a disability would be able to make.¹⁴³ Mr O'Donnell is a 32-year-old man who lives with cerebral palsy and an intellectual disability.¹⁴⁴ He told us while his parents were his guardians, they would not allow him to move to Melbourne as he wished and would not permit him to attend LGBTIQ+ community events.¹⁴⁵ Instead, Mr O'Donnell was forced to attend adult literacy and numeracy classes. For more than 10 years he was forced to stay in a job he did not enjoy.¹⁴⁶

A lack of engagement with the person under orders can limit a guardian or administrator's ability to make decisions reflecting the person's will and preferences. Mr Cartwright and Mr O'Donnell gave evidence they had limited face-to-face contact with Victorian State Trustees.¹⁴⁷ Other witnesses described poor communication from the public guardian or public trustee with them or their families about important decisions.¹⁴⁸

People can even be prevented from speaking publicly about their own experiences under guardianship and administration. Mr Cartwright made a documentary about his life titled *Life is a Battlefield*.¹⁴⁹ The documentary made limited reference to Mr Cartwright's proceedings before the Victorian Civil and Administrative Tribunal (VCAT) and his administrator, the Victorian State Trustees.¹⁵⁰ Mr Cartwright understood that in the days after the initial screening, VCAT wrote to the Special Broadcasting Service (SBS) stating its concerns that the documentary breached clause 37 of Schedule 1 of the *Victorian Civil and Administrative Tribunal Act 1998* (Vic) on confidentiality of proceedings.¹⁵¹ As a result, SBS removed the documentary from its website.¹⁵²

The documentary was later reinstated after Mr Cartwright made an application to VCAT to allow SBS to show the documentary.¹⁵³ Mr Cartwright told us VCAT ruled he could speak about his life, including his experience under an administration order, and publish his documentary.¹⁵⁴ In making this decision, VCAT referred to the need to balance the principle of open justice and Mr Cartwright being able to tell his story in public with the protection of people's privacy, which is the purpose of the public disclosure provisions.¹⁵⁵

Lack of cultural safety

Witnesses at Public hearing 30 gave evidence about the harm First Nations people experience from the lack of cultural safety while they are under guardianship or administration orders. For example, First Nations people have experienced removal from their support network, Country and cultural support¹⁵⁶ and shortcomings in medical treatment.¹⁵⁷

Anthony spoke about having to intervene to secure appropriate medical care for his mother, Killara.¹⁵⁸ He also spoke of some of the challenges Killara faced when she was under orders:

There was no Aboriginal workers or staff members at all when my mother was under guardianship until I became her medical guardian, and that's when I linked her into a cultural, safe health service. There was no [Aboriginal liaison officers] at the Public Advocate talking to myself or my mother. My mother – there was no cultural practices at all as well. It's so important, cultural yarning. She goes to cultural yarning groups now, weekly, fortnightly sometimes.

...

And there was limited attempts to make – make – sorry, limited attempts made to contact family. Absolutely. I wasn't even spoken to. It was hard to get hold of the guardian.¹⁵⁹

We discuss cultural safety and its importance further in Volume 9, *First Nations people with disability*.

Bringing guardianship and administration to an end

Lived experience witnesses at Public hearing 30 explained the barriers they faced when seeking a review or revocation of guardianship and administration orders. Ms Suzanne Nunn gave evidence on her family's experience with administration orders. Ms Nunn's two brothers lived with a disability and were both under administration orders appointing the Queensland Public Trustee. Ms Nunn told us they did not know they could have applied to QCAT to have orders appointing the Public Trustee revoked.¹⁶⁰

Austyn told us she applied for a review of Howie's guardianship orders. She said she had found some fact sheets about guardianship on the NSW Civil and Administrative Tribunal (NCAT) website, but still did not fully understand the process.¹⁶¹ NCAT said when Austyn applied for the review, NCAT's 'Review of guardianship orders' fact sheet was publicly available. It gave information on being represented by a lawyer.¹⁶² Austyn described the materials on the NCAT website as 'probably helpful if you are a lawyer or a solicitor, and you can interpret them. But not really to the lay person, no.'¹⁶³

Mr Cartwright had a VCAT hearing to consider having his administration order revoked. He expressed to VCAT that he did not wish to be subject to orders.¹⁶⁴ However, he did not know he needed to prove his capacity to manage his financial affairs. The administration order was extended for another six months.¹⁶⁵

Impacts of guardianship and administration

Guardianship and administration can have an impact on people's wellbeing, sense of self and relationships, in both the short and longer term. Mr O'Donnell told us how his parents were appointed as limited guardians and administrations, which gave them authority to make decisions on some personal matters and financial matters. He said the appointment affected his relationship with his parents:

I didn't see them as my parents anymore, they were just my guardians. It was really bad for us and changed our relationship. It caused a lot of fights. Sometimes I would be so upset, I would run out of the house screaming. I was living independently in the group home but was not allowed to make decisions for myself.¹⁶⁶

Mr O'Donnell also gave evidence about his experience being under administration orders appointing the Victorian State Trustee as financial administrator. Mr O'Donnell said their decisions have affected his wellbeing and his relationships.¹⁶⁷ He spoke about the stigma he experienced because he is under administration orders. He believed he could not get a rental property because people have a negative opinion of him for being under orders.¹⁶⁸

Ms Bury told us she was deeply affected by the experience of being under administration orders. She constantly wondered how she was perceived by others and whether an assessment of her capacity was being made without her knowledge.¹⁶⁹

Mr Cartwright spoke about the impact of an administration order on his day to day life:

I don't know the exact words but all I know is your life stops. It's just – you may as well be – you may as well have your identity stripped really. Like you can't do anything. Like I can't even go to the bank and, like, ask to withdraw money because if it's over the limit, (a), there is no money there; (b), you get given a card that State Trustee transfers money on a day that is predetermined, and if it's a dollar or two out of your agreed spending range you have to get an invoice and it takes two weeks. You just – you can't do anything. It's – yeah. You just stop existing in an odd way because you can still live, you still have freedoms, but you don't have freedoms.¹⁷⁰

Carlton and Jessye*

‘I have a non-verbal son with autism who’s been placed somewhere. He doesn’t understand why he can’t be at home and why he can’t see his friends.’

Carlton is a young autistic man in his early 20s with mental health issues.

His mother Jessye told the Royal Commission that not long after he finished school, he was taken from her by the public guardian.

‘And put under basically their control. And I was told, as a parent, that I have no say.’

The guardian placed Carlton in a group home. Jessye said there’s been ‘fraud, neglect, abuse’ under the service provider.

‘My son has suffered horrific abuse and bruising, which I’ve documented.’

Carlton is on a complex needs care package.

‘When this company became involved, they were given a million dollars.’

But for months, Jessye said, Carlton ‘had no therapies’ and ‘they stopped all his programs, stopped outings’.

‘They just drained his disability pension money. It’s always in debt. There is no money for him to be able to even buy himself anything, or just to go to the movies,’ Jessye said.

‘The supports that I had in place for my son, like an education program, he had his own therapists and stuff, that has all been taken away from him. All my people have all been sacked and they’ve just put in all these new people ... They basically are frauding the system. It’s just fleecing it. And they know they’re protected by the guardian.’

Jessye has been fighting for more than a year to have the guardianship order overturned.

‘Of course, I’ve tried everything. Every time I complain to the NDIS, the guardian shuts it down, saying there’s no issues.’

She recently appealed the guardianship at a tribunal but was unsuccessful. The hearing ignored evidence of ‘photos of locks on doors and restrictive practices being used’ at the home.

‘I supplied a five-page document ... and photos of what’s happened to my son and all the rest. And the member said, “We don’t have to look at evidence in this court. The guardian had said that he’s very happy with where they’ve placed your son.”’

Since then, Jessye ‘is not allowed to step foot in the property’.

‘I’ve had all those rights taken away.’

Jessye believed many parents have been ‘banned access to properties’ after they tried to get evidence of the abuse.

‘The care company have come back to the guardian and said that the parents were abusing the staff and basically put bullying charges onto us as parents ... And therefore, the guardian believes them and are not involving parents or therapists or people that are advocating for my son.’

Jessye said the exploitation of Carlton under the public guardian is one of hundreds of ‘horror stories’.

‘Some of the stories are more horrific than mine. I need to get rid of the guardianship board and take control back.’

Jessye said when Carlton comes home for weekends, he begs not to go back.

‘Staff come to get him and he screams on the lawn. He rolls around and runs away from them – “No. No. No.” I’ve sent videos to the guardian saying, “This is wrong. You’re forcing something on my son.” And I don’t even get an answer back.’

* This is a de-identified narrative of an experience shared with us in a submission or private session. The person who shared their experience was not a witness. They did not give evidence, take an oath or give an affirmation. Nothing in this narrative represents a finding of the Royal Commission and any views expressed are those of the person, not of the Royal Commission.

2.4. Moving towards supported decision-making

Several Australian and international jurisdictions, sectors and organisations have started to move away from substitute decision-making toward supported decision-making. The shift from substitute to supported decision-making has been described as a significant human rights development, particularly for people with cognitive disability.¹⁷¹

Public hearing 30 provided the opportunity to consider the relationship between autonomy and guardianship systems from a human rights perspective. In submissions for Public hearing 30, Counsel Assisting submitted that practices and laws that authorise substitute decision-making on the basis of disability undermine equal recognition before the law. Put simply, guardianship and administration laws apply exclusively to people with disability.¹⁷²

... I wouldn't have gone through any of it if I didn't have
a disability.¹⁷³

Reports and inquiries across Australian jurisdictions have described and recommended a move towards supported decision-making. They have led to some legal, policy and practice reforms that embed supported decision-making. Legal reform has primarily occurred in Victoria.

These reforms are consistent with a global movement towards supported decision-making. Internationally, a number of recent initiatives have increased recognition of and reliance on supported decision-making. These are described in the section on 'International initiatives' and they have informed the analyses and recommendations which follow.

Past reports and inquiries

Our terms of reference direct us to have regard to the findings and recommendations of previous relevant reports and inquiries.¹⁷⁴ A number of key reports recommending or demonstrating a move towards supported decision-making have informed our inquiry.

Equality, Capacity and Disability in Commonwealth Laws

In 2014, the Australian Law Reform Commission (ALRC) report, *Equality, capacity and disability in Commonwealth laws* (the ALRC report) recommended all jurisdictions reform laws and legal frameworks to formally recognise and promote supported decision-making in line with four principles and a decision-making model.¹⁷⁵ The four ALRC principles are:¹⁷⁶

-
- ALRC principle 1 – All adults have an equal right to make decisions that affect their lives and to have those decisions respected.
 - ALRC principle 2 – Persons who require support in decision-making must be provided with access to the support necessary for them to make, communicate and participate in decisions that affect their lives.
 - ALRC principle 3 – The will, preferences and rights of persons who may require decision-making support must direct decisions that affect their lives.
 - ALRC principle 4 – Laws, legal frameworks and policies must contain appropriate and effective safeguards in relation to interventions for persons who may require decision-making support, including to prevent abuse and undue influence.

The ALRC principles are supported by three guidelines:¹⁷⁷

- support guidelines
- will, preferences and rights guidelines
- safeguards guidelines.

These give guidance on how the principles should operate in practice.

The ALRC also recommended the introduction of a ‘Commonwealth decision-making model’ as a statutory mechanism in relevant laws and legal frameworks.¹⁷⁸ The key elements of the model are:¹⁷⁹

- amending the objects or principles provisions of relevant legislation
- the appointment, recognition, functions and duties of supporters and representatives (a representative is a person appointed to make decisions on behalf of another person)
- appropriate and effective safeguards.

The ALRC also recommended states and territories review laws and legal frameworks on individual decision-making to ensure they are consistent with the national principles and decision-making model. These frameworks include laws relating to guardianship and administration, consent to medical treatment and mental health and disability services.¹⁸⁰

The ALRC’s recommendations have been widely endorsed in Australia and recognised internationally.¹⁸¹ Many submissions to this Royal Commission and responses to issues papers also endorsed the ALRC’s recommendations.¹⁸²

The Australian Government has not formally responded to the ALRC report.¹⁸³ In 2018 the Australian Government informed the CRPD Committee that it was considering the recommendations in the ALRC report.¹⁸⁴ The CRPD Committee,¹⁸⁵ along with other countries during the Universal Periodic Review process,¹⁸⁶ has called on the Australian Government to implement the ALRC report recommendations.

Other national inquiries

Other major national inquiries have endorsed supported decision-making as a desirable alternative to substituted decision-making.¹⁸⁷

In its report *Elder abuse – a national legal response*, the ALRC highlighted the importance of supported decision-making as a safeguard. It noted that supported decision-making ‘offers an important safeguard against abuse for older people receiving aged care’.¹⁸⁸

Guardianship and administration also featured in the 2015 report of the Senate Community Affairs References Committee’s inquiry into violence against, and abuse and neglect of, people with disability in institutional and residential settings. It found guardianship arrangements in all jurisdictions require some reform, from improved guidelines on appropriate decision-making to the oversight of guardians themselves.¹⁸⁹

The Committee made recommendations to reform guardianship regimes and address these concerns.¹⁹⁰ For example, it recommended ‘the Australian Government consider driving a nationally consistent move away from substitute decision-making towards supported decision-making models’.¹⁹¹

In 2021, the Department of Social Services released a commissioned report, *Good practice in supported decision-making for people with disability*.¹⁹² The report aimed to develop guidelines for supported decision-making.¹⁹³

Reviews of guardianship and administration

At the state and territory level, there have been recent reviews of guardianship in Victoria, Queensland, the Australian Capital Territory, Western Australia, New South Wales and Tasmania.¹⁹⁴

The New South Wales Law Reform Commission (NSWLRC), Victorian Law Reform Commission (VLRC), Tasmanian Law Reform Institute (TLRI) and ACT Law Reform Advisory Council (ACTLRAC) have all made recommendations to introduce a formal supported decision-making scheme into guardianship laws.¹⁹⁵ These law reform bodies considered that a formal supported decision-making framework would provide an alternative, less restrictive option to decision-making.¹⁹⁶

There have also been specific reviews of the Public Trustee in Queensland, Victoria, Tasmania and Western Australia.¹⁹⁷ Other state and territories have also examined related issues in past reports. For example, in 2022 the South Australian Law Reform Institute (SALRI) published a report on decision-making capacity in the context of adult safeguarding laws in South Australia.¹⁹⁸

Legislative recognition of supported decision-making

Reforms to guardianship legislation have recently been implemented in Victoria and Queensland. Tasmania has also recently publicly consulted on proposed reforms to its guardianship legislation. These aim to modernise legislation and provide a greater emphasis on human rights.

The *Guardianship and Administration Act 2019* (Vic) represents a landmark reform to Victoria's guardianship system. The Act seeks to implement the ALRC's National Decision-Making Principles.¹⁹⁹ It provides a formal framework for supported decision-making. We discuss the Victorian legislation in more detail in the next section.

In Queensland, several amendments to the *Guardianship and Administration Act 2000* (Qld) came into effect on 30 November 2020. The Act introduced changes to the general principles and healthcare principles to align them with human rights, particularly those recognised in the *CRPD*.²⁰⁰ The Act also strengthened the presumption of capacity and emphasises participation in decision-making for adults with impaired decision-making ability.²⁰¹

In Tasmania, the Guardianship and Administration Amendment Bill 2023 (Tas) has been introduced into parliament.²⁰² It amends the *Guardianship and Administration Act 1995* (Tas) and *Tasmanian Civil and Administrative Tribunal Act 2020* (Tas). The Bill is intended to be part of a staged approach to modernising Tasmania's guardianship and administration system.²⁰³ It was developed as a response to the review of the *Guardianship and Administration Act 1995* (Tas) by the TLRI and addresses legislative matters arising from the independent review into the Public Trustee.²⁰⁴

The Bill was the subject of public consultation in October and November 2022. The Attorney-General presented the Bill and delivered its First Reading in the House of Assembly on 28 March 2023.

The *NDIS Act* explicitly acknowledges the need for people with disability to make decisions affecting them.²⁰⁵ The NDIA stated this means, as a starting point, adult participants have the ability to make their own decisions about the NDIS.²⁰⁶ Mr McNaughton and Dr Bennett from the NDIA stated supported decision-making underpins the general principles of the *NDIS Act* including:²⁰⁷

- principle 4 – support to take reasonable risks
- principle 8 – ability to determine own best interests and engage as partners in decisions
- principle 9 – dealings and communications with the NDIA.

Supported decision-making in Victoria

In our view, the legislation most compliant with human rights principles and the *CRPD* is Victoria's guardianship and administration legislation. It is at present the only guardianship and administration law in Australia that expressly provides a supported decision-making scheme.²⁰⁸

Key legislative provisions

The key provisions under the *Guardianship and Administration Act 2019* (Vic) include:

- the presumption of decision-making capacity is strengthened, in that a person is taken to have decision-making capacity in relation to a matter if it is possible for the person to make the decision with ‘practicable and appropriate support’,²⁰⁹ unless there is evidence to contrary²¹⁰
- a list of general principles to which a person exercising a power, carrying out a function or performing a duty under the Act must have regard. For example, they must:²¹¹
 - provide practicable and appropriate support to a person with disability who requires support to enable them to make and participate in decisions that affect them, express their will and preferences, and develop their decision-making capacity
 - as far as practicable, make decisions that reflect the will and preferences of a person with disability
 - exercise, carry out and perform powers, functions and duties under the Act in a way that is the least restrictive of the ability of a person with a disability to decide and act as is possible in the circumstance.
- a list of decision-making principles to which a person making a decision for a represented person must have regard. For example, they must:²¹²
 - give all practicable and appropriate effect to a represented person’s will and preferences
 - give effect as far as practicable to the represented person’s likely will and preferences. If a person’s actual will and preferences cannot be determined, decisions must be based on all information available, including information obtained by consulting the represented person’s relatives, close friends and carers
 - promote a represented person’s personal and social wellbeing if their likely will and preferences cannot be determined
 - act in a manner that recognises the importance of the companion animal to the represented person if they have one
 - only override a represented person’s will and preferences if necessary to prevent serious harm to the represented person.
- conferral of power on the VCAT to appoint a supportive guardian or supportive administrator for a person with disability who is 18 years or older. The person appointed as a supportive guardian or administrator has certain powers designed to support the person with disability to make decisions in relation to personal or financial matters, formalising supported decision-making arrangement.²¹³
- removal of plenary substitute decision-making appointments (which allow appointed decision-makers to make decisions across all areas of a person’s life).

We discuss Victoria's supported decision-making scheme further in Section 2.5.

Other law reform measures

The *Powers of Attorney Act 2014* (Vic), authorises individuals to appoint a 'supportive attorney' to provide them with decision-making support.²¹⁴ Supported decision-making is also recognised and included in the *Mental Health Act 2014* (Vic) and the *Medical Treatment and Planning Decisions Act 2016* (Vic).²¹⁵ The mental health and wellbeing principles of the new *Mental Health and Wellbeing Act 2022* (Vic), which will come into effect in September 2023, include a principle on supported decision-making.²¹⁶ Under this principle, persons receiving mental health and wellbeing services must be supported to make decisions. They must also be involved in decisions about their assessment, treatment and recovery including when they are receiving compulsory treatment.²¹⁷

Number of supportive guardians and administrators appointed

Between 1 March 2020, when the *Guardianship and Administration Act 2019* (Vic) commenced, and until November 2022, VCAT received 229 applications for supportive guardianship and made 71 appointments of supportive guardians.²¹⁸ In this time VCAT received 189 applications for supportive administration, and made 99 appointments of supportive administrators.²¹⁹

Dr Pearce acknowledged that relatively few supportive orders have been made.²²⁰ The reasons include:²²¹

- family members may be either unwilling or not suitable to assume the role
- the proposed represented person may have no family member or other person in their life who could perform the role
- the absence of any publicly funded service able to act as supportive guardian or administrator.

In some cases, guardianship or administration orders may be made where there is no suitable or willing person able to act as a supportive guardian or supportive administrator.

Dr Pearce said:

In the absence of anyone suitable and willing to accept appointment as supportive guardian or supportive administrator, VCAT will often proceed to make a guardianship or administration order even where the proposed represented person would likely have decision-making capacity if they had appropriate support.²²²

Ms Naomi Anderson from Villamanta Disability Rights Legal Service said if supportive guardianship or administration is going to work effectively awareness of the need for decision-making support is needed so that appropriate supports can be identified and provided.²²³

Dr Pearce's office recently prepared a report that reviewed the operation of the *Guardianship and Administration Act 2019* (Vic). It concluded that while the legislation recognises the important role of supported decision-making, this has not been enough to ensure people's right to autonomy is promoted to the fullest extent possible.²²⁴ To address this, the OPA announced its intention to undertake a pilot project to implement recommendations contained in the report, including by:²²⁵

- undertaking short-term advocacy in appropriate matters using a supported decision-making approach
- providing education to service system organisations through direct engagement with workers
- delivering education to staff at organisations that are part of the service system, to both smaller and larger groups, and via a short video that will be developed as part of the project.

Supported decision-making practice

Supported decision-making can be provided formally (under an order or through services) and informally (by family and friends). Regardless of how supported decision-making occurs, it is important decision supporters have a good understanding of how to provide supported decision-making in practice. A number of witnesses have described some key features and elements of supported decision-making practice.

Representatives from the Council for Intellectual Disability gave evidence about how models of supported decision-making might be developed in practice. They said that supported decision-making models should be:²²⁶

- developed with the leadership of people with disability
- directed to advancing the human rights of a person with disability
- designed with accepted principles and centred around the person's right to support
- developed for different circumstances.

They said supported decision-making involves considering reasonable adjustments a person may need:

adjustments means making a change to get a fair result. So, they help to meet the needs of a person. An individual adjustment may be using a communication device to say a choice. A bigger system adjustment may be changing a policy to say people have the right to make their own legal decisions with support. Adjustments are important because change in the world around the person helps them make more of their own decisions.²²⁷

Witnesses emphasised the will and preferences of the person needing supported decision-making should direct the decisions that are made.²²⁸ However, this can take time and resources. For supported decision-making to work it is crucial to know the person being supported.²²⁹

As part of supported decision-making, the decision supporter may also need to provide information and explain options. Representatives from Queensland Advocacy for Inclusion (QAI) described the informal supported decision-making provided to 'Tracey' by an advocate (the decision supporter) when she was setting up her NDIS plan in a regional area. Before Tracey's plan meeting, the decision supporter held face-to-face meetings with her and established her goals and support needs. After the plan meeting, the advocate supported Tracey in making informed decisions that 'suited her preferences'.²³⁰ Ms Matilda Alexander from QAI observed:

[Tracey's case was an] example of how much work does need to go into good supported decision-making. This is not a process that's necessarily efficient. It's not a process that will lead to the quickest outcomes or the easiest outcomes, the way substitute decision-making sometimes can be seen to. But it is a process that supports a person's inherent personhood and human rights.²³¹

Supported decision-making should also accommodate people to make decisions when their decision-making ability is reduced.²³² Mr Craig Gear is from the Older Persons Advocacy Network, which promotes the rights of older people, including older people with disability.²³³ He described an approach for people who may experience fluctuating decision-making ability. He said in the same way as a person can give an advance care directive, an advance social directive can record a person's will and preferences.²³⁴ Mr Gear explained an advance social directive is:

similar to an advanced care directive, which is often about the way I want to die, an advanced social directive is about how I want to live. And that can be how I want to live in my intimate relationships. It's about how I want to be treated, about how – when I might have fluctuating capacity how someone will engage with me, provide me space to still make decisions. It is a filmed will, in that sense, and could be attached to someone's My Health Record or to their My Aged Care Record which gives instructions to anyone interacting with that person – friends, family, care workers – about how that person wants their interactions and care to be delivered and what works for them.²³⁵

Supported decision-making pilots and resources

There have been many supported decision-making pilots and programs in Australia and in overseas jurisdictions.²³⁶ Several pilots have been completed and evaluated.²³⁷ Most aimed to implement a system of supported decision-making for people with a form of cognitive disability.²³⁸

There is an increasing evidence base about the effectiveness of supported decision-making on the lives of people with disability.²³⁹ According to the report, *Diversity, dignity, equity and best practice: A framework for supported decision-making*, the pilots and programs demonstrate that supported decision-making is most effective when people with disability already know the supporter or, if they are socially isolated, can get to know the supporter. This is necessary to build trust.²⁴⁰

The report identified best-practice training resources, including:²⁴¹

- the La Trobe Framework for Decision-making Practice Framework, which is based on a program of research about supported decision-making practice with people with intellectual disability and acquired brain injuries²⁴²
- the Supported decision-making for people with dementia package, which is based on a three-year project with people with dementia, professionals and family members and other research about supported decision-making.²⁴³

Both resources have similar elements, but they also demonstrate the differences between various groups, particularly between people with a stable cognitive disability and people with an increasing need for support.²⁴⁴

Tools have also been developed globally to educate and guide people about the concept and practice of supported decision-making.²⁴⁵ The audience for these resources generally comprises people with disability and their supporters,²⁴⁶ with specific guidance for groups such as legal professionals²⁴⁷ and medical practitioners and allied health professionals.²⁴⁸ Some tools have a specific focus such as communication for people with dementia,²⁴⁹ or developing a ‘personal factors inventory’.²⁵⁰

International initiatives

There have been international initiatives to recognise and promote supported decision-making. Mexico,²⁵¹ Israel,²⁵² Argentina,²⁵³ Peru²⁵⁴ and a number of European countries,²⁵⁵ as well as jurisdictions in Canada²⁵⁶ and the United States,²⁵⁷ have taken measures to formally recognise and implement supported decision-making.

Canada has been considered to be at the forefront of ‘embedding alternatives to substitute decision-making in guardianship legislation’.²⁵⁸ The Province of British Columbia is seen as ‘one of the leading jurisdictions in incorporating supported decision-making into law, policy and practice’.²⁵⁹ In British Columbia, a person can enter into a ‘representation agreement’, appointing representatives to help them make decisions on their behalf. A representation agreement retains substitute decision-making as an option, but only if the person chooses that option. Regardless of whether the person chooses to appoint someone as a supporter or substitute decision-maker, the agreements emphasise respect for the person’s wishes, beliefs and values.²⁶⁰ However, research has found there has been a limited uptake, largely due to legal and health communities not promoting or embracing use of representation agreements.²⁶¹

In Alberta, legislation provides for supported decision-making and co-decision-making.²⁶² New Brunswick recently passed a law providing for the appointment of a decision-making assistant, decision-making supporter or, as a last resort, a representative.²⁶³

Sweden’s so-called ‘god man’ is another version of a legally recognised supporter. An appointment is generally made with the consent of the person who will be supported, although there are exceptions.²⁶⁴

Costa Rica, Colombia, Peru and Mexico have eliminated from their legal frameworks all forms of guardianship for people with disability.²⁶⁵ However, whether this means substitute decision-making will be abolished in practice is still being determined. Other jurisdictions retain guardianship as an option of last resort.²⁶⁶ Ireland, for example, introduced the *Assisted Decision Making (Capacity) Act* in 2015, which incorporates supported decision-making approaches but retains guardianship as a last resort.²⁶⁷

The United States has also developed a model law on guardianship that, among other things, requires a court to rule out supported decision-making as an option before appointing a guardian or conservator, or making another protective arrangement.²⁶⁸ At the time of writing, the model law has been enacted in two states, while other states are incorporating references to supported decision-making in their statutes.²⁶⁹

2.5. A new supported decision-making framework

We consider state and territory guardianship and administration legislation should be reformed to better recognise and embed supported decision-making. Reforms should ensure guardianship and administration is only used as a last resort, in line with a principled approach to supported decision-making. This is critical to enabling the autonomy of people with disability.

The principles of last resort and least restriction are expressed in different ways across jurisdictions, and there is variation in how they inform substantive provisions on guardianship and administration appointments.²⁷⁰ The increasing number of applications for guardianship or administration (discussed in Section 2.3) suggests guardianship and administration orders are not being made as a last resort and in the least restrictive manner.²⁷¹ There is inconsistency between principle and practice.

Following Public hearing 30, Counsel Assisting submitted it was open to the Royal Commission to recommend the Australian Government and state and territory governments develop a new assisted decision-making regime for guardianship and administration orders. This regime should:

- include changes to the approach to assessing a person's capacity with a focus on:
 - decision-making ability, as distinct from independent assessment of capacity
 - fluctuating decision-making ability
 - review of decision-making ability as circumstances change
- move away from 'best interests' to rights, interests and opportunities
- require the will and preferences of the relevant person be the primary consideration
- require uniform decision-making principles to be applied when assisting the relevant person
- require the relevant person be provided with all necessary supports and reasonable accommodations
- exercise substitute decision-making only as a last resort and in clearly identified circumstances.²⁷²

We agree with this submission. We recommend a new supported decision-making framework and describe the reforms needed to embed it in the relevant state and territory guardianship and administration legislation.²⁷³

We use the term ‘supported decision-making’, rather than ‘assisted decision-making’, to avoid introducing new and potentially confusing terminology. This is consistent with the Australian Government’s response, which noted any recommendation should use the term ‘supported decision-making’, based on feedback from the disability community on strong preferences for this term.²⁷⁴

The key aspects of the supported decision-making framework we recommend are:

- use of modern language and terminology
- inclusion of the *CRPD* in the objects of legislation
- focus on decision-making ability
- introduction of a formal supporter model
- ensuring representatives are appointed only as a last resort
- providing a new decision-making process for supporters and representatives.

These elements build on the work of past reports and reviews, and recent legislative reforms in Victoria, discussed in Section 2.4.

Incorporating key elements of a supported decision-making framework in all guardianship and administration legislation will bring about greater uniformity and consistency in practice across states and territories. States and territories will still be able to incorporate elements reflecting their particular circumstances and the views expressed by their law reform bodies.

States and territories should consider additional amendments to support implementation of the supported decision-making framework. For example, they should consider:

- reviewing and updating provisions concerning representatives such as:
 - their functions, powers and duties
 - safeguarding provisions
 - review and revocation of orders
- mutual recognition of appointments across states and territories
- transitional provisions.

Modern language and terminology

The language of guardianship can carry paternalistic connotations.²⁷⁵ It is increasingly recognised that language about disability needs to move away from this. Changing language in guardianship and administration legislation would reflect a more contemporary and human-rights based approach to disability and decision-making.

Reviews of state and territory guardianship systems have recommended guardianship legislation uses simple and accessible language.²⁷⁶ We agree guardianship terminology should be simplified so people can understand and safeguard their rights. It will also assist the community in understanding the roles and responsibilities of people who provide decision-making support or make decisions on behalf of another person.²⁷⁷

In Recommendations 6.4 to 6.10, we have adopted the terms and definitions in Table 6.2.11. These terms are based on the terms and definitions recommended by the NSWLRC.²⁷⁸

Table 6.2.11: Terms and definitions

Term	Definition
Decision-making ability	The ability of a person to make a particular decision with the provision of relevant and appropriate support at a time when a decision needs to be made.
Enduring representation agreement	An arrangement under which a person appoints an enduring representative to make decisions for them when they do not have decision-making ability for those decisions.
Enduring representative	A person appointed by another person under an enduring representation agreement to make decisions for them.
Representation order	A statutory order under which a tribunal appoints a representative to make certain decisions for another person who does not have decision-making ability for those decisions, as a measure of last resort.
Representative	A person appointed under a representation order to make decisions on behalf of another person.
Represented person	A person who has a representative or enduring representative appointed to make a decision when they do not have decision-making ability for that decision.
Support agreement	An arrangement under which a person formally appoints a supporter to assist them in making decisions.
Support order	A statutory order, made by a tribunal, that appoints a supporter to assist a person to make their own decisions.
Supported person	A person who is supported in making decisions by a supporter appointed under a support order or support agreement.
Supporter	A person appointed under a support order or support agreement to support someone else in making decisions.

‘Supporter’ and ‘representative’

We recommend use of the terms ‘supporter’ and ‘representative’ to refer to appointments of supporters and substitute decision-makers. These terms were proposed by the ALRC, and have been adopted by the TLRI, the ACTLRAC and the NSWLRC in their guardianship reviews.²⁷⁹

The ALRC used the term ‘supporter’ to ‘reflect the role played by an individual or organisation that provides a person with the necessary support’ to make decisions. The term ‘indicates that ultimate decision-making power and responsibility remains with the person, with support being provided to assist them in making the decision themselves’.²⁸⁰

The term ‘representative’ signals ‘the role of a representative is to support and represent the will, preferences and rights’ of a person who requires decision-making support.²⁸¹ The ALRC considered using these terms would address the lack of clarity underpinning the language of substitute and supported decision-making.²⁸²

Presently, legislation in all states and territories uses the terms ‘guardianship’ and ‘administrator’ or financial ‘manager’ to allow for the formal appointment of a substitute decision-maker.²⁸³ Victorian legislation refers to formal appointments of supporters as ‘supportive guardian’ and ‘supportive administrator’.²⁸⁴ This is contrary to the VLRC recommendation in its 2010 review of the *Guardianship and Administration Act 1986* (Vic), which was to use the term ‘supporter’.²⁸⁵

‘Decision-making ability’

The concept of capacity is subject to a number of assumptions that compromise the autonomy and rights of people with disability. We propose the term ‘ability’ when referring to whether a person is able to make decisions.

The concept of ‘capacity’ and the language used to describe a lack of capacity is inconsistent across state and territory legislation. Guardianship and administration legislation variously describe a person’s ‘decision-making capacity’,²⁸⁶ ‘impaired decision-making ability’,²⁸⁷ ‘capacity’,²⁸⁸ ‘mental incapacity’,²⁸⁹ or ‘need [for] a guardian’ if a person is ‘incapable of managing their affairs’.²⁹⁰

In submissions following Public hearing 30, Counsel Assisting preferred the term ‘decision-making ability’ because it properly addresses the need for support to be provided in a person’s exercise of decision-making rights.²⁹¹

Law reform bodies have also recommended this term.²⁹² The NSWLRC suggested framing ability – rather than disability – reflects a move away from outmoded aspects of the *Guardianship Act 1987* (NSW).²⁹³ The *Guardianship and Management of Property Act 1991* (ACT) similarly refers to ‘impaired decision-making ability’.²⁹⁴

The ALRC report considered that ‘all adults, except in very limited circumstances, have some level of decision-making ability and should be entitled to make decisions’, according to their will and preferences, even if they require varying levels of support to do so.²⁹⁵ According to

the ALRC's recommended support guidelines, a person's decision-making ability is central to assessing the need for supported decision-making.²⁹⁶

Many factors outside a person shape the person's ability to make a particular decision. This includes the quality of any support relationships, the complexity of the relevant decision, and available time and resources. The supported decision-making principles recognise the ability to make decisions with the provision of relevant and appropriate support when needed (see Recommendation 6.6).

We consider the term 'decision-making ability' should be used in all circumstances covered by guardianship and administration legislation. This includes the making and operation of support orders and representation orders, and support agreements and enduring representation agreements. A focus on decision-making ability is addressed further in Recommendation 6.7.

Recommendation 6.4 Terms and definitions in guardianship and administration legislation

- a. States and territories should amend their guardianship and administration legislation to:
 - include the terms 'support order', 'support agreement' and 'supported persons'
 - remove the terms 'guardianship order' and 'administration order' or 'financial management order', and replace these with 'representative order'
 - remove the terms 'guardian' and 'administrator' or 'financial manager', and replace these with 'representative'
 - remove the term 'enduring guardian' and replace this with 'enduring representative'
 - remove the terms 'enduring guardianship' and 'enduring power of attorney' and replace these with 'enduring representation agreement'
 - remove the terms 'decision-making capacity', 'capacity' and 'mental incapacity' and replace these with 'decision-making ability'.
- b. The new and replacement terms should be defined consistently with the definitions provided in Table 6.2.11.
- c. States and territories should amend the title of their guardianship and administration legislation to refer to decision-making. For example, 'Supported and represented decision-making Act' or 'Decision-making Act'.

We have adopted the language recommended in Recommendation 6.4 in this report, except when referring to current provisions in legislation. We use 'guardianship and administration legislation' to refer to current legislation in states and territories.

Recognising human rights in the objects of guardianship law

There is a long way to go to ensure that human rights principles are recognised and implemented in practice. One way to advance this is through a statement of statutory objects in guardianship and administration legislation that expressly:

- recognise the rights of people with disability consistent with the *CRPD*
- include the text of article 12 of the *CRPD*
- recognise the role of support for decision-making.

Recent reforms in Victorian and Queensland have recognised the *CRPD*.²⁹⁷ In Victoria, the *Guardianship and Administration Act 2019* (Vic) recognises the *CRPD* as the means of implementing the primary object of the Act, which is to protect and promote the human rights and dignity of persons with a disability.²⁹⁸

The *Guardianship and Administration Act 2000* (Qld) is also expressed in terms broadly consistent with article 12. It acknowledges the fundamental right to make decisions, dignity of risk and proportionality, as well as access to decision-making support.²⁹⁹ The Act's stated purpose is to strike an appropriate balance between the right of adults with impaired capacity to the greatest possible degree of autonomy in decision-making and the adult's right to adequate and appropriate support for decision-making.³⁰⁰ In addition, it includes the general principle that the adult's equal entitlement to enjoy human rights and fundamental freedoms must be recognised.³⁰¹ Clearly, the legislative intention is to implement Australia's obligations under article 12(3) in a manner consistent with Australia's interpretative declaration.

Several law reform bodies have referred to the need to recognise the principles of the *CRPD* in guardianship and administration legislation.³⁰² The NSWLRC recommended a statement of statutory objects including that the objects of the Act are to:

- (i) implement the purposes and principles of the *CRPD*
- (ii) promote the independence and personal and social wellbeing of people in need of decision-making assistance and provide safeguards in relation to the activities governed by the Act.³⁰³

The Guardianship and Administration Amendment Bill 2023 (Tas) also proposes to recognise and implement the principles of the *CRPD* in the objects of the *Guardianship and Administration Act 1995* (Tas).³⁰⁴

Recommendation 6.5 complements human rights legislation in the Australian Capital Territory,³⁰⁵ Victoria³⁰⁶ and Queensland.³⁰⁷ These laws require public authorities, such as tribunal members, guardians and financial administrators, to act consistently with the human rights included in the relevant Act. These human rights laws all recognise that everyone has the right to recognition as a person before the law.³⁰⁸

Recommendation 6.5 Objects of guardianship and administration legislation

States and territories should review and reform their guardianship and administration legislation to include a statement of statutory objects which:

- recognises and promotes the rights of people with disability consistent with the *Convention on the Rights of Persons with Disabilities (CRPD)*
- includes the text of article 12 of the *CRPD*
- recognises the role of support to enable people who may require support to make, participate in and implement decisions that affect their lives.

Supported decision-making general principles

We agree with Counsel Assisting's submission that the Australian Government and state and territory governments adopt uniform national decision-making principles. These should include:³⁰⁹

- Principle 1 – Recognition of the equal right to make decisions
- Principle 2 – Presumption of decision-making ability
- Principle 3 – Respect for dignity and the right to dignity of risk
- Principle 4 – Recognition of the role of informal supporters and advocates
- Principle 5 – Access to support necessary to communicate and participate in decisions
- Principle 6 – Decisions should be directed by a person's own will and preferences and rights
- Principle 7 – Inclusion of appropriate and effective safeguards against violence, abuse, neglect and exploitation
- Principle 8 – Co-design, co-production and peer-lead design processes
- Principle 9 – Recognition of the diverse experiences, identities and needs of persons
- Principle 10 – Entitlement to culturally safe, sensitive and responsive decision-making support.

We agree these principles should be given legislative effect.³¹⁰ This will require decision-makers who are exercising a power, carrying out a function or performing a duty to take the principles into account.³¹¹ The principles are designed to implement a supported decision-making framework, among other objectives.

The principles in Recommendation 6.6 have broad application across various systems and contexts. We consider that governments should also take steps to review and reform other laws concerning decision-making using the supported decision-making principles as the basis

for this reform. This is consistent with Counsel Assisting's submission that the Australian Government and state and territory governments should develop a new assisted decision-making regime with respect to substitute decision-making for decisions other than guardianship and administration orders.³¹²

Principle 1 – Recognition of the equal right to make decisions

All people have an equal right to make decisions and to have those decisions respected.

Principle 1 is based on article 12 of the *CRPD*. The ALRC started with this principle because it adopts the 'paradigm shift' incorporated in the *CRPD*.³¹³ We agree.

Only Queensland currently recognises a right to make decisions in its general principles.³¹⁴ Victoria acknowledges the right as one of the primary objects of the *Guardianship and Administration Act 2019* (Vic).³¹⁵

Principle 2 – Presumption of decision-making ability

All people must be presumed to be able to make decisions.

We consider a presumption that each person has decision-making ability should be the starting point for determining whether or not a person is capable of making their own decision. Starting with a person's legal capacity, the focus should be on ensuring supports are in place.³¹⁶ This is consistent with recognition under article 12 that people with disability enjoy legal capacity on an equal basis with others in all aspects of their life.³¹⁷

The Australian Government's reply submissions in Public hearing 30 accepted a supported decision-making framework should start from the presumption that a person has decision-making ability. The submissions referred to the evidence from Dr Bennett of the NDIA, who said:

where capacity or decision-making ability is defined as a static concept, there is an inherent risk that a person may be labelled as lacking it, which could have an unintended consequence of curtailing that person's choice and control.³¹⁸

A presumption of legal capacity exists in common law.³¹⁹ However, not all states and territories recognise it in guardianship and administration legislation. The common law presumption does not necessarily have the same force, either as a matter of principle or of practice, as a presumption embedded in legislation. There is no statutory presumption of legal capacity in guardianship and administration legislation in New South Wales, South Australia, Tasmania or the Australian Capital Territory.

Victoria, Queensland, Western Australia and the Northern Territory incorporate a statutory presumption of a person's capability to make decisions. This is generally framed as 'decision-making capacity'³²⁰ or 'capacity'.³²¹ Western Australia refers to this presumption as 'capability'.³²²

Recent law reform reports have proposed that a presumption of decision-making ability should be included in guardianship and administration legislation.³²³ The NSWLRC, for example, supported introducing a statutory presumption of decision-making ability or capacity into guardianship and administration law to:³²⁴

- help ensure that the regime aligns with article 12 of the *CRPD* and facilitate a human rights approach to decision-making
- perform an educative function
- provide an additional safeguard against inappropriate application of the law
- assist people with particular types of mental illness and physical disability who are commonly presumed to lack decision-making ability.

However, the ALRC refrained from translating the right to make decisions into a presumption. It preferred to emphasise the substantive right to make decisions, rather than rely on a presumption which can be rebutted by evidence.³²⁵

While we understand these concerns, we consider there is merit in a principle expressed as a presumption of decision-making ability. We agree with the NSWLRC's assessment and consider it will ensure the focus in an application for a representative order is on the person's ability to make decisions.

Principle 3 – Respect for dignity and dignity of risk

All people must be treated with dignity and respect and supported to take risks to enable them to live their lives the way they choose, including in their social and intimate relationships.

Respect for inherent dignity forms part of the first general principle of the *CRPD*.³²⁶ We consider this includes entitlement to dignity of risk, with support if necessary. This means a person with disability should be able to take reasonable risks, and to make and learn from mistakes. This is not always the case for people with disability under guardianship and administration orders. A tension emerges when a person with disability wants to make a decision about their life that has an associated risk, for example the risk of financial loss. Guardianship and administration legislation does not recognise that people with disability are entitled to take risks in the same way as other adult members of the community. As Ms Anderson from Villamanta Disability Rights Legal Service Inc said at Public hearing 30, 'how does anyone learn from their mistakes if the only response is to take control away from them completely?'.³²⁷

Although the ALRC did not include a principle recognising dignity of risk, its Support Guidelines captured the principle by rejecting an outcomes-based approach to assessing decision-making ability.³²⁸ The report, *Diversity, dignity, equity and best practice: A framework for supported decision-making*, included a principle designed to ensure that dignity and the importance of taking risks is acknowledged and supported.³²⁹

The Aged Care Quality Standards explicitly refer to 'consumer dignity and choice' and require organisations to demonstrate that '[e]ach consumer is supported to take risks to enable them to live the best life they can'.³³⁰ The Standards also require organisations to provide support for decision-making.³³¹

The CRPD Committee highlighted the need to recognise and enable dignity of risk. It said that while there is the need to protect people from undue influence, this protection must respect 'the right to take risks and make mistakes'.³³² A principle is needed which recognises and respects dignity *and* dignity of risk as central elements in decision-making, including supported decision-making.

Principle 4 – Recognition of informal supporters and advocates

The role of informal supporters, support networks and advocates who provide support for decision-making should be acknowledged and respected.

In Public hearing 30, witnesses gave evidence about the role of informal supporters and advocates in providing support for decision-making, including support to navigate the guardianship and administration system.³³³ Informal supported decision-making arrangements can ensure people with disability avoid more formalised substitute decision-making arrangements.

Legislation in Victoria, New South Wales, Queensland, South Australia and the Northern Territory includes principles which recognise, in various ways, the role of informal support relationships.³³⁴ Queensland provides the most extensive requirements in recognising informal support relationships.³³⁵

The Victorian scheme also acknowledges relationships of support, such as with family and carers, while ensuring that the person with disability retains the right to make their own decisions. It provides formal acknowledgment of these relationships of support, and recognition and certainty for third-party interactions.³³⁶

The TLRI adopted Queensland's approach and recommended a guiding principle on 'the role of families, carers and other significant persons in an adult's life to support the adult to make decisions should be acknowledged and respected'.³³⁷ The Support Guidelines the ALRC proposed also acknowledged the role of family members, carers or others as supporters.³³⁸

The inclusion of a principle recognising the role of informal support relationships implicitly endorses the use of informal support for decision-making, consistent with the *CRPD*.³³⁹ It also makes it more likely that support relationships are formalised only where existing informal support is not working.³⁴⁰

We expand on advocacy and informal supports in Chapter 3.

Principle 5 – Access to support

People who may require supported decision-making should be provided with equitable access to appropriate support to enable the person, as far as practicable in the circumstances, to:

- make and participate in decisions affecting them
- communicate their will and preferences
- develop their decision-making ability.

Article 12(3) of the *CRPD* provides that States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity. Principle 5 follows article 12(3) and is adapted from a general principle in Victoria's *Guardianship and Administration Act 2019* (Vic):³⁴¹

(a) a person with a disability who requires support to make decisions should be provided with practicable and appropriate support to enable the person, as far as practicable in the circumstances—

- (i) to make and participate in decisions affecting the person; and
- (ii) to express the person's will and preferences; and
- (iii) to develop the person's decision-making capacity.

We consider this to be a positive articulation of a person's right to be provided with support when it is needed to make decisions. The principle recognises the importance of people with disability developing decision-making skills so they can exercise their right to make decisions.³⁴² The Judicial College of Victoria has observed that, although this principle does not describe who provides support or how it may be given, it reflects the shift in focus from the challenges facing a person with disability to the supports that should be provided.³⁴³

We have expanded on the principle in Victoria's *Guardianship and Administration Act 2019* (Vic) to specify equitable access to appropriate support. This is drawn from the report, *Diversity, dignity, equity and best practice: A framework for supported decision-making*. One of the nine principles the report proposed was:

Distributional equity. All supported decision-making reform and initiatives should be premised on the ethical principle of a commitment to distributional equity of access to supported decision-making. Those experiencing disadvantage in accessing supported decision-making should be given priority in new programs.³⁴⁴

We replaced ‘express’ with ‘communicate’ in the second point to recognise that support should ensure a person’s will and preference is received and understood by other parties. At Public hearing 30, for example, we heard how Simeon Namok’s sister, Kernisha, is able to understand his body language, so she can give effect to his will and preferences and support his decision-making.³⁴⁵ We discuss communication in more detail in Chapter 1, ‘Accessible information and communications’.

The third and final point is consistent with evidence we have heard on the need to provide support to develop people’s decision-making ability.³⁴⁶ Building skills and providing support for decision-making may enhance people’s autonomy.³⁴⁷ A principle on access to supports has been embedded into the principles of guardianship legislation in the Northern Territory and in Queensland.³⁴⁸ The Guardianship and Administration Amendment Bill 2023 (Tas) has also modelled its proposed principle concerning supported decision-making on Victoria’s framing.³⁴⁹

We draw on the process for supported decision-making provided in the ALRC’s Support Guideline further in Recommendation 6.10 on decision-making process.

We note the potential for either a professional or volunteer decision supporter scheme, which could involve advocates potentially acting as decision supporters. Dr Pearce gave evidence that the lack of a service or program of this nature was as a major barrier to the making of supportive orders under the *Guardianship and Administration Act 2019* (Vic). She said this in turn has limited the realisation of the Act’s primary object of promoting the rights and dignity of persons with disability.³⁵⁰ We encourage the Australian Government and states and territories to further consider the development of a decision supporter scheme.

Principle 6 – Decisions directed by will and preferences

The will and preferences of people who may require supported decision-making must direct decisions that affect their lives.

As discussed earlier in the chapter, a principled approach to supported decision-making requires a person’s stated or perceived ‘will and preferences’ to be at the centre of decision-making. This was raised in evidence by several witnesses with considerable experience in this area.³⁵¹

The phrase ‘will and preferences’ derives from the *CRPD*, although neither the *CRPD* nor the CRPD Committee provides specific guidance on what the expression means. In the recent report, *Good Practice in Supported Decision-making for People with Disability* prepared for the Department of Social Services, the following definitions were given:

- 'will' means larger life goals, political perspectives, emotional and spiritual development and views, gender and sexuality identity for example
- 'preferences' means choices regarding day-to-day- activities, aesthetic preferences, and similar
- 'will' and 'preferences' is also regularly connected with 'rights' in the sense that supported decision-making is about giving effect to the will, preferences and rights of a person requiring decision-making support.³⁵²

A 'will and preferences' approach is different from the 'best interests' approach, where the decision-maker is guided by their perception of what would be most appropriate for the represented person.³⁵³ One witness described 'best interests' as incorporating 'we know best' ideas above the person's wishes and preferences.³⁵⁴

We should not be acting in the best interests of people.
We need to be acting in line with their wishes and preferences
and to be able to document and understand those from the
person or from their history ...³⁵⁵

Several jurisdictions retain the 'best interests' standard in legislation.³⁵⁶ Law reform bodies have consistently recommended changes to guardianship legislation so that substitute decision-makers are required to give effect to a person's will and preferences where possible.³⁵⁷ The VLRC for example, said:

the continued use of 'best interests' as the primary consideration for substitute decision makers is unhelpful because it would impede evolution of the practice of acting in a manner that respects the rights, will and preferences of represented persons to the maximum possible extent.³⁵⁸

The TLRI considered it important to base decisions on a person's will and preferences because:³⁵⁹

- every person should have the ability to make decisions that affect their life
- people without disability are not required to establish that a decision is rational, or in their best interests
- decisions based on a person's perceived best interests tend to overemphasise safety and restrict the right of all people to take risks and make mistakes.

In Victoria, the general principles in the *Guardianship and Administration Act 2019* (Vic) provide that 'the will and preferences of a person with disability should direct, as far as practicable, decisions made for that person'.³⁶⁰

Queensland guardianship legislation and the proposed reforms in Tasmania use the phrase ‘views, wishes, and preferences’.³⁶¹ The TLRI preferred this because it provides greater clarity and is consistent with language in the current *Guardianship and Administration Act 1995* (Tas).³⁶²

To ensure consistency across states and territories, we recommend the phrase articulated in the *CRPD*, ‘will and preferences’, be adopted as the standard phrase in legislation.

Principle 7 – Inclusion of safeguards

There must be appropriate and effective safeguards where people may require supported decision-making, including to prevent abuse and undue influence.

In Volume 3, we discussed the ways in which being under guardianship and administration can impact on health, safety, wellbeing and relationships.

We consider safeguards are needed in guardianship and administration processes to minimise risk of undue influence and coercion. This would recognise the unequal relationships between the people being supported and their supporters and representatives.³⁶³ Safeguards would protect a person who requires decision-making support from risk of violence, abuse, neglect or exploitation. They would ensure that supported decision-making arrangements genuinely respond to and reflect the wishes of a person with disability.³⁶⁴

The ALRC recommended both a principle and guideline on safeguards.³⁶⁵ Principle 7 is consistent with the ALRC’s recommended principle on safeguards and the requirements of article 12(4) of the *CRPD*.

Principle 8 – Co-designed processes

People with disability, in particular people with cognitive disability, their supporters and representative organisations, should be involved in the development and delivery of policies and practices on supported decision-making.

At Public hearing 30, representatives from the Council for Intellectual Disability emphasised that people with disability should lead the development of supported decision-making practices.³⁶⁶ This means directing the conversation, deciding what is good support, and providing training on supported decision-making.³⁶⁷

Following Public hearing 17, ‘The experience of women and girls with disability with a particular focus on family, domestic and sexual violence’, Counsel Assisting submitted:

Effective implementation of a rights-based approach requires the needs of people

with disability to be prioritised in system design, interventions, and service responses. Implementation of this approach should occur across prevention, early intervention, response and recovery, in collaboration with people with disability and the disability services sector. This draws on the principle of ‘nothing about us without us’, and the requirement to consult and work alongside people with disability.³⁶⁸

The Victorian Government told us a true process of co-design involves people with disability sharing systems of power.³⁶⁹ A co-design process involves partnering and collaborating with people with lived experience in each aspect of design. It includes developing proposed approaches and alternatives, and identifying preferred solutions.³⁷⁰

The report, *Diversity, dignity, equity and best practice: A framework for supported decision-making* recommended the following as part of its proposed nine principles:

Co-leadership of people with cognitive disabilities. People with cognitive disability and supporters of people with ‘severe’ cognitive disability should lead consultation and design processes for supported decision-making initiatives.³⁷¹

Consistent with the proposed principle, we recommend Principle 8 specifically identify people with cognitive disability.

We consider the principle will encourage greater focus and involvement of people with disability in the development of supported decision-making initiatives, models and resources under reformed guardianship and administration legislation.

Principle 9 – Recognition of diversity

The diverse experiences, identities and needs of people who may require supported decision-making must be actively considered.

Lived experience witnesses at Public hearing 30 demonstrated the diversity of people’s experiences, identities and needs in the context of substitute and supported decision-making. The report *Diversity, dignity, equity and best practice: A framework for supported decision-making* recognised the importance of diversity:

people who need support for some or all decisions, differ in terms of type and severity of cognitive impairment, personal attributes and identity such as age, gender, sexuality, cultural background, socioeconomic status and other forms of human diversity. Those differences impact in various ways, including: whether and how cognitive abilities change over time; the extent and nature of social connections; the service systems they engage with; personal histories of living with or without a cognitive disability; cultural expectations relating to autonomy and forms of support; geographical and economic barriers and enablers to accessing formal and informal support.³⁷²

Several participants at the policy roundtables identified a need for supported decision-making principles to better accommodate the diverse characteristics of people with disability. They referred to people with fluctuating capacity, people with the ability to make some but not all decisions, and people who can make certain decisions with the right environmental conditions such as access to information and sufficient time to process that information.³⁷³

Victoria's *Mental Health and Wellbeing Act 2022* (Vic) provides an example of a diversity principle. The Act states that the 'diverse needs and experiences of a person receiving mental health and wellbeing services are to be actively considered noting that such diversity may be due to a variety of attributes'. These attributes are said to include gender identity, sexual orientation, sex, ethnicity, language, race, religion, faith or spirituality, class, socioeconomic status, age, disability, neurodiversity, culture, residency status and geographic disadvantage.³⁷⁴ It also requires mental health and wellbeing services are to be provided in a manner that:³⁷⁵

- is safe, sensitive and responsive to the diverse abilities, needs and experiences of the person including any experience of trauma
- considers how those needs and experiences intersect with each other and with the person's mental health.

We consider that Principle 9 will encourage persons exercising powers, carrying out functions or performing duties under guardianship and administration legislation to consider diverse disability-related support needs and diverse social and cultural contexts.

Principle 10 – Cultural safety

First Nations people and culturally and linguistically diverse people with disability are entitled to supported decision-making that is culturally safe, sensitive and responsive. This includes recognising the importance of maintaining a person's cultural and linguistic environment and set of values.

It is important for supported decision-making to be provided in a culturally safe way for people with disability from First Nations and culturally and linguistically diverse backgrounds. Following Public hearing 30, Counsel Assisting submitted that guardians and administrators must be aware of the ways in which people's culture affects their decision-making ability and, equally importantly, how culture will support their decision-making ability.³⁷⁶

During Public hearing 25, 'The operation of the NDIS for First Nations people with disability in remote and very remote communities', we heard about what cultural safety can look like for First Nations people with disability requiring decision-making support. The Northern Territory Public Guardian, Beth Walker, explained that, in considering which service provider to recommend for a First Nations person under guardianship, public guardians are 'heavily guided by the views of people that we are representing, and so it's about their level of comfort in – and safety in using a service provider'.³⁷⁷ Patricia Turner AM, the CEO of the National Aboriginal Community

Controlled Health Organisation, explained how cultural respect and cultural safety can best be guaranteed by Aboriginal community-controlled services, which are highly visible and trusted in First Nations communities.³⁷⁸

Only Victorian, New South Wales and Queensland legislation provides some recognition of people's cultural and linguistic environment and values in principles.³⁷⁹ These principles inform the second part of Principle 10.

We discuss cultural safety for First Nations people in more detail in Volume 9.

Recommendation 6.6 Supported decision-making principles

- a. States and territories which have not already done so should review and reform their guardianship and administration legislation to include the following supported decision-making principles. The legislation should oblige all persons exercising powers, carrying out functions or performing duties under the legislation to have regard to the principles.

Principle 1 – Recognition of the equal right to make decisions

All people have an equal right to make decisions that affect their lives and to have those decisions respected.

Principle 2 – Presumption of decision-making ability

All people must be presumed to be able to make decisions.

Principle 3 – Respect for dignity and dignity of risk

All people must be treated with dignity and respect and supported to take risks to enable them to live their lives the way they choose, including in their social and intimate relationships.

Principle 4 – Recognition of informal supporters and advocates

The role of informal supporters, support networks and advocates who provide support for decision-making should be acknowledged and respected.

Principle 5 – Access to support

People who may require supported decision-making should be provided with equitable access to appropriate support to enable the person, as far as practicable in the circumstances, to:

- make and participate in decisions affecting them
- communicate their will and preferences
- develop their decision-making ability.

Principle 6 – Decisions directed by will and preferences

The will and preferences of people who may require supported decision-making must direct decisions that affect their lives.

Principle 7 – Inclusion of safeguards

There must be appropriate and effective safeguards where people may require supported decision-making, including to prevent abuse and undue influence.

Principle 8 – Co-designed processes

People with disability, in particular people with cognitive disability, their supporters and representative organisations, should be involved in the development and delivery of policies and practices on supported decision-making.

Principle 9 – Recognition of diversity

The diverse experiences, identities and needs of people who may require supported decision-making must be actively considered.

Principle 10 – Cultural safety

First Nations people and culturally and linguistically diverse people with disability are entitled to supported decision-making that is culturally safe, sensitive and responsive. This includes recognising the importance of maintaining a person's cultural and linguistic environment and set of values.

- b. The Australian Government and state and territory governments should also take steps to review and reform other laws concerning individual decision-making to give legislative effect to the supported decision-making principles.

Focus on decision-making ability

Support people's ability. Believe their decision-making capability can be grown and developed over time. For example, letting them make small decisions and building it up. Letting them do small bits of work and be a part of decisions around the house. Helping them feel equal.³⁸⁰

Principle 2 of the supported decision-making principles states that all people should be presumed to be able to make decisions. Recommendation 6.7 gives further guidance on implementing this principle.

Counsel Assisting submitted it is open to us to recommend that, if the presumption that a person has decision-making ability may be rebutted, a guideline should be developed with a nationally consistent set of factors to be considered as to whether the presumption should be rebutted.³⁸¹

We agree, but rather than recommending a guideline, we propose that criteria should be given legislative status. We have developed the criteria based on existing legislative provisions and recommendations from past reports. States and territories may wish to establish guidelines complementing these criteria to support their consistent implementation. Public guardians or public advocates would be well placed to develop the guidelines.

Rebutting the presumption – assessing decision-making ability

State and territory guardianship and administration laws take different approaches to defining and assessing a person's capacity or decision-making ability. In most jurisdictions a person must have a disability for a guardianship or administration order to be made.³⁸² Disability is not explicitly required for an order in Queensland, the Northern Territory and the Australian Capital Territory.³⁸³ For example, in Queensland, a person has 'impaired capacity' if they do not have capacity for a matter.³⁸⁴ 'Capacity' is defined as a person being capable of understanding the nature and effect of decisions about the matter, freely and voluntarily making decisions about the matter and communicating the decision in some way.³⁸⁵ While disability is not referred to, the definition of impaired capacity is similar to definitions of 'decision-making' disability in other jurisdictions.³⁸⁶

In Victoria, when deciding whether to make an order, VCAT must be satisfied that, because of the person's disability, the person does not have decision-making capacity for the decision concerned.³⁸⁷ The VLRC recommended the link to disability remain in guardianship laws because it gives an objective element to the test. According to the VLRC, this ensures that people do not come under guardianship orders because they engage in harmful behaviour that is not the direct result of a disability.³⁸⁸ In introducing the Victorian legislation, which adopted the VLRC's approach, the Victorian Attorney-General said:

The definition (of decision-making capacity) is intended to prevent unnecessary appointments of guardians and administrators. VCAT will not be able to appoint a guardian or administrator simply because a person has a disability, or because someone else thinks that the person is making unwise decisions.³⁸⁹

Past reports and more recent guardianship reviews have proposed avoiding use of the term 'disability' as a criterion for determining whether a substitute decision-making order may be required.³⁹⁰ The TLRI considered that removing the need for a disability will ensure people with disability have the equal right to make decisions, including where others might consider their decisions 'irrational' or 'poor'.³⁹¹

In a 2023 report, the Victorian OPA also recommended the reference to 'disability' be removed from the *Guardianship and Administration Act 2019* (Vic) where this relates to the appointment of a guardian or administrator. The OPA considered this would ensure the focus is on whether the person does not have decision-making capacity for a particular matter, rather than the person not having decision-making capacity because of their disability.³⁹²

In their Support Guidelines the ALRC proposed assumptions about the extent of decision-making support should not be based on a person's disability.³⁹³

We consider a person's disability should be relevant only to the extent where it affects their ability to make or carry out decisions. For this reason, Recommendation 6.7 provides the presumption that a person has decision-making ability cannot be rebutted just because a person has a disability.

Recent reviews of guardianship laws have also acknowledged a person's decision-making ability can vary depending on the circumstances. The NSW Legislative Council Standing Committee on Social Issues recommended acknowledging 'the fact that a person's decision-making capacity varies from domain to domain and from time to time'.³⁹⁴ The VLRC noted the need to 'accommodate different levels of cognitive ability and decision-making needs' through flexibility in the law and an 'individualised approach to assessment'.³⁹⁵ The Queensland Law Reform Commission acknowledged that any consideration of capacity should take into account that 'impaired capacity' may be partial, temporary or fluctuating.³⁹⁶

As noted at the start of this section, Counsel Assisting submitted a new assisted decision-making regime should include changes to the approach to assessing a person's capacity with a focus on:³⁹⁷

- fluctuating decision-making ability
- review of decision-making ability as circumstances change.

Consistent with this submission and past reports, the Royal Commission recommends in considering whether to rebut the presumption of decision-making ability, a decision-maker must consider:

- that decision-making ability is specific to the decision being made
- the nature and complexity of the particular decision to be made.

We also recommend the decision-maker must consider the support available to the person and the views of family and informal supporters. This is to operationalise supported decision-making principles 4 and 5.

Recommendation 6.7 Decision-making ability

States and territories should review and reform their guardianship and administration legislation to:

- ensure consistency with Principle 2 in Recommendation 6.6 that all people should be presumed to be able to make decisions
- provide that this presumption cannot be rebutted solely on the basis that a person has a disability

-
- require that anyone responsible for deciding whether the presumption has been rebutted that a person has decision-making ability for the relevant decision, must consider:
 - the supports available to the person, including the quality of existing support relationships
 - that decision-making ability is specific to the decision being made
 - the nature and complexity of the specific decision to be made
 - the views of the person and, with their consent, the views of family and informal supporters who have significant involvement in the person's life.

Formal supporter model

The supported decision-making framework should incorporate a formal supporter model. This model recognises and gives legal standing to people providing decision-making support, and imposes requirements to protect the person receiving support. In doing so, it provides an alternative to the appointment of a representative.

Recent reviews of guardianship and administration in New South Wales, Tasmania and the Australian Capital Territory have recommended incorporating a formal supporter model.³⁹⁸ The TLRI summarised the main reasons for introducing this model into legislation as:³⁹⁹

- the importance of recognising the legitimate role of decision-making support
- the need for oversight and other safeguarding mechanisms to avoid the potential abuse or undue influence of informal supporters
- improving the quality and availability of decision-making supports
- providing another strategy to ensure that a representative decision is only made as a last resort.

As explained in Section 2.4, Victoria is the only jurisdiction that currently recognises and enables formal supporters in guardianship legislation.⁴⁰⁰ The *Powers of Attorney Act 2014* (Vic) also enables a person to appoint their own supportive attorney.⁴⁰¹

A summary of Victoria's supported decision-making scheme is outlined in Table 6.2.12.

Table 6.2.12: Summary of Victorian supported decision-making scheme⁴⁰²

Formal supported decision-making scheme – key elements	<i>Guardianship and Administration Act 2019 (Vic)</i>	<i>Powers of Attorney Act 2014 (Vic)</i>
Appointment of supporters	VCAT may make a supportive guardianship order or supportive administration order (section 87) Persons eligible as supportive guardians or supportive administrators (section 88) Matters to be specified in supportive guardianship orders and supportive administration orders (section 89)	Power to make and scope of appointment (section 85) Who may make a supportive attorney appointment (section 86) Persons eligible as supportive attorney (sections 91–93) Execution of appointment (section 95)
Powers and duties of supporters	Powers of supportive guardians or supportive administrators (section 90) Information power (section 91) Communication power (section 92) Power to give effect to decisions (section 93) Duties and obligations of supportive guardians and supportive administrators (section 94)	Information power (section 87) Communication power (section 88) Powers as to giving effect to decisions (section 89) Duties and obligations of supportive attorney (section 90)
Safeguards in relation to supporters	No entitlement to remuneration (section 95) When a supportive guardianship order or supportive administration order ceases to have effect (section 96) Advice from VCAT on the scope of an order (section 97)	Persons eligible to sign an appointment form (section 96) Persons eligible to witness signing an appointment form (section 97) Certification of witness to signing an appointment form (section 98) Acceptance by supportive attorney (s 99) Effect of appointment if principal does not have decision-making capacity (section 102)

Formal supported decision-making scheme – key elements	<i>Guardianship and Administration Act 2019 (Vic)</i>	<i>Powers of Attorney Act 2014 (Vic)</i>
Review and revocation of supportive orders	Reassessment (section 159) Matters to be included in application (section 160) Parties to a reassessment (section 161) Notice of reassessment (sections 162–163) Conduct of reassessment on VCAT's initiative (section 164) Participation of supported person at hearing (section 165) VCAT consideration (section 166) Order after reassessment (section 167)	Revocation of appointment by principal (section 103) Other revocation by supportive attorney (section 109)

During Public hearing 30, Mr Cartwright told us about his experience being under an administration order. Reflecting on his recent experience of having a supportive guardian appointed at VCAT,⁴⁰³ he said it is his choice and he is in control of the arrangement.⁴⁰⁴

We consider Victoria's approach provides a model for other jurisdictions to follow when introducing a formal supporter model.

Recommendation 6.8 accommodates both statutory (tribunal) and personal appointment of supporters. This is consistent with various law reform commission recommendations which considered this allowed the model to cater for a broad range of circumstances.⁴⁰⁵ It also allows people with a wide network of family and friends to choose personal appointment, and for people with limited access to informal supporters to benefit from tribunal assistance through an appointed supporter.⁴⁰⁶

Recommendation 6.8 Formal supporters

States and territories should introduce into guardianship and administration legislation provisions to enable statutory and personal appointments of one or more supporters for personal and financial matters, following the approach taken by Victoria in Part 4 of the *Guardianship and Administration Act 2019 (Vic)* and Part 7 of the *Powers of Attorney Act 2014 (Vic)*. This includes provisions on:

- appointment of supporters
- role, powers and duties of supporters
- safeguards in relation to supports
- review and revocation of support agreements and orders.

Representatives as a last resort

In our recommended supported decision-making framework, representation orders replace guardianship and administration orders. A representation order would be a statutory order under which, as a measure of last resort, a tribunal appoints a representative to make certain decisions for another person who does not have decision-making ability for those decisions.

To ensure representative decision-making is used as a last resort in practice, guardianship and administration legislation needs to be amended to:

- repeal plenary orders
- specify the circumstances in which a representation order can be made
- ensure in-person participation of a person in a hearing
- specify additional factors to consider when deciding whether to make a representation order for a First Nation person.

Repealing plenary orders

Generally, a ‘plenary’ or ‘full appointment’ guardianship or administration order gives a guardian or administrator authority over all of a person’s personal or financial matters.⁴⁰⁷ The VLRC described a plenary guardian’s powers as ‘being akin to that of a parent in relation to a child’.⁴⁰⁸

Legislation in Victoria, the Australian Capital Territory and Northern Territory does not allow for plenary orders.⁴⁰⁹ In these jurisdictions a tribunal is required to tailor its orders.

The *Guardianship and Administration Act 2019* (Vic) identifies matters must be specified in guardianship, administration and supportive orders.⁴¹⁰ The Northern Territory requires Northern Territory Civil and Administrative Tribunal (NTCAT) to ‘specify in a guardianship order the personal matters or financial matters, or both personal matters and financial matters, for which the guardian has authority’.⁴¹¹ In Tasmania, the Guardianship and Administration Amendment Bill 2023 (Tas) proposes repealing the provision enabling full guardianship appointments and requiring the Tasmanian Civil and Administrative Tribunal (TASCAT) to specify the personal matters for which a guardian is required.⁴¹²

Although orders for plenary guardianship are rare,⁴¹³ law reform bodies have recommended their abolition. They suggest the order should specify a representative’s functions or the types of decisions the representative can make.⁴¹⁴

Making a representation order

We recommend guardianship and administration legislation should provide that the tribunal may only appoint a representative where it is satisfied:

- the proposed represented person does not have decision-making ability for one or more decisions
- there is a need for the order, considering
 - the will and preferences of the proposed represented person
 - the availability and suitability of less intrusive and restrictive measures, including formal and informal support arrangements, negotiation and mediation
- the order will promote the person's personal and social wellbeing.

Lack of decision-making ability for one or more decisions

A representation order should only be made where a person does not have decision-making ability for one or more decisions. This is also consistent with the NSWLRC and TLRI recommendations regarding grounds for making a representation order.⁴¹⁵

For the reasons described under Recommendation 6.7, we consider disability should not be a necessary condition or ground for making a representation order. This will also ensure the focus remains on a person's decision-making ability.

The need for an order

Before making an order, the tribunal should be satisfied of the 'need' for an order. This should take into account the will and preferences of the person and whether there are less intrusive and restrictive measures available. This aligns with Principle 4: Recognition of informal supporters and advocates and Principle 6: Decisions directed by will and preferences of the supported decision-making principles (see Recommendation 6.6).

All states and territories recognise a version of the principle of least restriction in their general principles.⁴¹⁶ However, the language varies.

Legislation in most states and territories also provides criteria the tribunal must consider when determining whether a guardianship or administration order is appropriate and is the least restrictive measure in the circumstances.⁴¹⁷ However, the criteria vary across jurisdictions. Also, there is not always an explicit requirement to consider informal measures (in addition to the least restrictive requirement) before a representative is appointed.

The NSWLRC recommended, as a necessary circumstance for a representation order, the tribunal should take into account whether less intrusive and restrictive measures are neither available nor suitable.⁴¹⁸ This recommendation is designed to ensure the order complies with the principle of least restriction and is only made as a last resort when formal and informal arrangements are not sufficient.

In Victoria, in determining the need for a guardianship or administration order, VCAT must consider:⁴¹⁹

- the will and preferences of the proposed represented person (so far as they can be ascertained)
- whether decisions about the personal or financial matter for which the order is sought
 - may more suitably be made by informal means
 - may reasonably be made through negotiation, mediation or similar means
- the wishes of any primary carer or relative of the proposed represented person or other person with a direct interest in the application
- the desirability of preserving existing relationships that are important to the proposed represented person.

We consider the Victorian approach is most in line with a human rights approach for the same reasons expressed by the TLRI.⁴²⁰ We have reflected the key aspects of the Victorian provisions in our recommendation.

The order will promote the person's personal and social wellbeing

Finally, we consider it necessary to specify that a representation order should only be made where it will promote the person's personal and social wellbeing.

In Victoria, in determining whether to make a guardianship or administration order, VCAT is required to consider whether the order will promote the proposed represented person's personal and social wellbeing.⁴²¹ The same consideration is proposed in Guardianship and Administration Amendment Bill 2023 (Tas).⁴²²

Queensland and the Australian Capital Territory include a requirement that, without an appointment, the adult's needs will not be met or the adult's interests will not be adequately protected.⁴²³

Eligibility and suitability for appointment as a representative under a representation order

Recommendation 6.9 also outlines criteria the tribunal must consider when considering whether a person is suitable for appointment as a representative. These reflect the criteria recommended by the NSWLRC.⁴²⁴ They are also broadly similar to the criteria for suitability of a guardian or administrator used in other states and territories.⁴²⁵ The criteria include whether a represented person has a conflict of interest. This will be particularly relevant where the proposed representative is providing paid services to the proposed represented person.

Participation of proposed represented person in proceedings

Recommendation 6.9 also requires in-person attendance by the proposed represented person in hearings concerning the representation order, unless the tribunal is satisfied it would not be feasible or appropriate. We consider this is an important safeguard and would support broader efforts to ensure the will and preferences of a person with disability are able to be meaningfully heard. See section 2.6 for further discussion on maximising the participation of people with disability in tribunal proceedings.

The wording is adapted from provisions in the *Guardianship and Administration Act 2019* (Vic).⁴²⁶ There is no similar provision on participation of the represented person in hearings concerning an application for a guardianship or administration order in legislation across other states and territories.

Specific considerations for First Nations people

Data indicates that First Nations people are overrepresented in every state guardianship and administration system (see section 2.3). To respond to this, we recommend tribunals take into account additional factors specific to First Nations people when considering whether to make a representation order. These are based on NSWLRC recommendations that the Tribunal have regard to:⁴²⁷

- the likely impact of the order on the person's culture, values, beliefs (including religious beliefs) and linguistic environment
- the likely impact of the order on the person's standing or reputation in their Indigenous community
- any other relevant consideration pertaining to the person's culture.

Participants at the policy roundtable on guardianship also supported reforms for cultural safety. These would include a need to consider the specific circumstances of First Nations people, having regard to cultural or linguistic factors, when determining the decision-making ability of First Nations people.⁴²⁸

This recommendation complements Principle 10 – Cultural safety (see Recommendation 6.6).

Review and revocation of representation orders

One of the challenges identified at Public hearing 30 was ending guardianship and administration orders.⁴²⁹ Public guardians and public trustees said a key barrier to revoking guardianship and/or administration orders was that most orders are not self-executing – that is, they do not end after a set period of time.⁴³⁰

The Victorian Public Advocate and the Queensland Public Guardian said that greater use of time-limited orders with a self-executing expiry would help address issues in having guardianship orders reviewed.⁴³¹ The NSWLRC also supported the inclusion of time limits on the duration of representation orders.⁴³²

An expiry date on representation orders and regular reviews of orders are ways to ensure consideration of whether the order is still required or should be varied or removed due to changes in circumstances. This is consistent with article 12 of the *CRPD*, which states measures must be proportional and tailored to the person's circumstances and apply for the shortest time possible.⁴³³

Recommendation 6.9 requires a representation order to lapse three years after the date on which it is made, unless the tribunal has specified an expiry date (earlier than three years) in the order or the order is renewed. This is similar to requirements in Tasmania and the Northern Territory. In Tasmania, a guardianship or administration order lapses on the expiration of three years after the date it is made unless an application for review of orders is made.⁴³⁴ In the Northern Territory, a guardianship order must specify a review date and an expiry date.⁴³⁵

Regular periodic review

Recommendation 6.9 also requires the tribunal review a representation order at least once within each three-year period after it is made. Periodic reviews of orders provide an additional safeguard, consistent with article 12 of the *CRPD*. Article 12 states that measures dealing with the exercise of legal capacity should be 'subject to regular review by a competent, independent and impartial authority or judicial body'.⁴³⁶

Most states and territories provide various timeframes for review of orders in legislation.⁴³⁷ Regular or periodic review is not required in Tasmania or the Northern Territory. In the Northern Territory, a review must be specified in the order unless the order expires earlier than one year after it is made. Tasmania does not include any time frame in legislation.⁴³⁸

Given the evidence we heard in Public hearing 30 about the lack of accessible information about applying for a review in some jurisdictions (see section 2.3), regular review would help ensure people are not under representation orders for longer than necessary.

Factors to consider on review

Recommendation 6.9 sets out the factors the tribunal should consider when reviewing an order to ensure consistency and the least restrictive approach is applied. These factors are consistent with the NSWLRC recommendation which requires the tribunal to consider, where relevant:⁴³⁹

- whether there is still a need for the order
- whether eligibility and suitability criteria for a representative are still met
- whether the representative is meeting their responsibilities and carrying out their required functions.

State and territory legislation differ on including factors a tribunal must consider on reviewing a guardianship or administration order.

In Victoria and the Northern Territory, the tribunal is required to consider the role of the guardian or administrator appointed and assess whether they have performed their duties in compliance with the Act.⁴⁴⁰ In South Australia this is limited to providing that the tribunal may conduct a review in such a manner as it thinks fit.⁴⁴¹

Queensland legislation has a provision on an appointment review process, which enables QCAT to conduct a review of an appointment of a guardian or administrator in the way it considers appropriate.⁴⁴² For a review of an appointment, QCAT can also require the guardianship or administrator to provide advice about appropriateness and competence.⁴⁴³

New South Wales, Western Australia, Tasmania and the Australian Capital Territory do not specify any factors the tribunal must consider when it reviews an order.

Recommendation 6.9 Representatives as a last resort

States and territories should review and reform their guardianship and administration legislation to provide that representation orders should be made only as a last resort and in a way that is least restrictive of a person's rights, autonomy and actions, as practicable in the circumstances. The reforms should include:

- a. the repeal of provisions authorising plenary representation orders
- b. a requirement that the relevant tribunal should make an order appointing a representative only if satisfied that:
 - the proposed represented person does not have decision-making ability for one or more decisions
 - the order is necessary, taking into account:
 - the will and preferences of the proposed represented person
 - the availability and suitability of less intrusive and restrictive measures, including formal and informal support arrangements, negotiation and mediation
 - the order will promote the person's personal and social wellbeing
- c. a provision that the tribunal must take into account, in deciding whether a person (other than a public official) is suitable for appointment as a representative:
 - the will and preferences of the proposed represented person
 - the nature of the relationship between the proposed representative and the proposed represented person
 - whether the proposed representative is likely to act honestly, diligently and in good faith
 - whether the proposed representative has or may have a conflict of interest in relation to any of the decisions referred to in the order

-
- d. a prohibition on a representation order made in the absence of the proposed represented person, unless the tribunal is satisfied that either:
 - the represented person does not wish to attend the hearing in person
 - the personal attendance of the represented person at the hearing is impracticable or cannot reasonably be arranged
 - e. a requirement that when considering whether a support or representation order should be made for a First Nations person, the tribunal should take into account:
 - the likely impact of the order on the person's culture, values, beliefs (including religious beliefs) and linguistic environment
 - the likely impact of the order on the person's standing or reputation in their community
 - any other considerations pertaining to the person's culture
 - f. provisions on the review and revocation of representation orders, including that:
 - a representation order lapses on the expiration of three years after the date on which it is made, unless the tribunal has specified an expiry date (earlier than three years) in the order or the order is renewed
 - a tribunal must conduct a review of a representation order at least once within each three-year period after making the order
 - when reviewing an order, the tribunal should consider:
 - whether the order is still necessary considering the factors listed in b.
 - whether the representative is still eligible and suitable
 - whether the representative is meeting their responsibilities and carrying out their required functions.

Decision-making process

Recommendation 6.10 focuses on the decision-making process appointed supporters and representatives must follow to provide support or make decisions. The process we recommend is consistent with a principled approach to supported decision-making and builds on other recommendations in this section.

The starting point, in both cases, is that decisions must be directed by the will and preferences of the person needing decision-making support. This is consistent with ALRC's will, preferences and rights guidelines.⁴⁴⁴

Best interpretation of will and preferences

In limited circumstances where a representative cannot identify a person's will and preferences, a principled approach to supported decision-making allows for a decision to be based on the representative's best interpretation of what the person's will and preferences would be.⁴⁴⁵ In other words, a representative decision maker who is unable to ascertain a person's will and preference on a particular matter is directed to consider what this might be, rather than resorting to their own views about what may be best for the person. This approach continues to centre 'will and preferences', rather than adopting a 'best interests' approach.

The research report, *Diversity, dignity, equity and best practice: A framework for supported decision-making* explained how the need for a 'best interpretation of will and preferences' standard, in limited circumstances, demonstrates how support and substitution cannot be viewed in opposition. Rather these lie along a spectrum.⁴⁴⁶ One respondent to the research said:

There is something in the middle there where you are really trying to make a decision that's really honouring the person's participation and really trying to identify their wishes even when that's incredibly difficult but acknowledging that there's a whole heap of interpretation going on there, so you can't be sure that that is what the person wants.⁴⁴⁷

The best interpretation of will and preferences standard is consistent with views expressed by the CRPD Committee⁴⁴⁸ and law reform bodies.⁴⁴⁹

The Victorian legislation provides, as part of its decision-making principles, that a person making a decision for a represented person must have regard to the principle that:

if the person is not able to determine the represented person's will and preferences, the person should give effect as far as practicable in the circumstances to what the person believes the represented person's will and preferences are likely to be, based on all the information available, including information obtained by consulting the represented person's relatives, close friends and carers.⁴⁵⁰

This is consistent with ALRC's will, preferences and rights guidelines, which require that, in cases where the 'will and preferences of a person cannot be determined, the representative must give effect to what the person would likely want, based on all the information available, including by consulting with family members, carers and other significant people in their life'.⁴⁵¹

We have adopted a similar approach in Recommendation 6.10. Principle 4 recognises the role of informal supporters and advocates (see Recommendation 6.6), which would include assisting a representative decision-maker to determine what a person's will and preference would likely be.

Promoting personal and social wellbeing

If a supporter cannot determine what the person would likely want, despite their best efforts to do so, we consider the standard of decision-making should be to ‘promote a person’s personal and social wellbeing’. This should be done ‘with the least possible restriction on their dignity and autonomy’.

This approach is broadly consistent with the ALRC’s will, preferences and rights guidelines which provide that:

If it is not possible to determine what the person would likely want, the representative must act to promote and uphold the person’s human rights and act in a way least restrictive of their human rights.⁴⁵²

It is also consistent with the Victorian legislation, which uses the ‘promote a person’s personal and social wellbeing’ standard.⁴⁵³ The *Guardianship and Administration Act 2019* (Vic) describes the meaning of ‘promote the personal and social wellbeing of a person’ by providing a non-exhaustive list of ways that personal and social wellbeing is promoted. These include recognising a person’s inherent dignity and individuality; having regard to existing supportive relationships, religion, values and cultural and linguistic environment; respecting a person’s confidentiality; and recognising the importance of a person’s companion animal.⁴⁵⁴ What is meant by ‘personal and social wellbeing’ will depend on each individual’s circumstances.⁴⁵⁵

The NSWLRC and TLRI both recommended adopting the Victorian standard of promoting a person’s personal and social wellbeing if a person’s will and preferences cannot be determined.⁴⁵⁶ The NSWLRC said this would provide ‘a conscious move away from the “welfare and interests” approach to a more person-centred approach’.⁴⁵⁷ While noting the application of personal and social wellbeing will depend on each person’s individual circumstances, the NSWLRC provided an example of how this could be used in practice:

Using a ‘personal and social wellbeing’ standard should emphasise to decision-makers that money is to be used for the person’s overall welfare, including spending on items that make the person’s life more enjoyable.⁴⁵⁸

The TLRI said consideration of a person’s ‘personal and social wellbeing’ provides more clarity than ‘rights’ because it adopts more commonly used language that may be more easily understood.⁴⁵⁹ The TLRI also considered the phrase ‘personal and social wellbeing’ promotes a rights-based approach.⁴⁶⁰

Serious harm

We also consider there is a need for guidance on and a definition of the limited circumstances in which decision-making may depart from a person’s will and preferences. Without guidance, decision-makers might adopt a default ‘best interests’ approach.⁴⁶¹

In Victoria, decision-makers are required to follow the will and preferences of the person, unless to do so would cause ‘serious harm’ to the represented person.⁴⁶² The legislation does not define ‘serious harm’. Also, it does not consider whether a person’s wishes can be overridden to prevent serious harm to a third person.⁴⁶³ VCAT has held that serious harm includes:

- serious financial harm to the represented person⁴⁶⁴
- exposing a represented person to unnecessary risk living without assistance services.⁴⁶⁵

Dr Pearce explained the process at the Victorian OPA is to ascertain the degree of risk and management of risk. A decision to override the person’s will and preferences must be made in consultation with a manager and appropriately recorded. This is designed to ensure accountability for decisions departing from a person’s will and preferences.⁴⁶⁶

The ALRC’s guidelines did not set a threshold at which harm may allow departure from a person’s will and preference. It only speaks to the possibility of considering ‘harm’.⁴⁶⁷ The TLRI suggested that, to avoid uncertainty or ambiguity, ‘harm’ should include harm to the person, or to another person.⁴⁶⁸

The NSWLRC took a different approach. It instead focused on ‘unacceptable risk’ as the threshold at which a person’s will and preferences may not be followed. Instead, the standard of ‘promoting a person’s personal and social wellbeing’ must be followed.⁴⁶⁹

We consider the Victorian threshold criterion of ‘serious harm’ to be preferable. As discussed in respect of Principle 3: Dignity and dignity of risk of the supported decision-making principles (see Recommendation 6.6), a focus on risk presents a barrier to people exercising their right to make decisions.

Where a representative decision-maker overrides a person’s will and preference to prevent serious harm, the decision-making standard that should apply is ‘promoting a person’s personal and social wellbeing with the least possible restriction on their dignity and autonomy’. This is reflected in the recommendation.

Recommendation 6.10 Decision-making process

States and territories should review and reform their guardianship and administration legislation to include a decision-making process that appointed supporters and representatives are required to follow.

The decision-making process for both supporters and representatives should involve:

- supporting the person to express their will and preferences
- assisting the person to develop their own decision-making ability.

The decision-making process for representatives should also include the following steps and considerations:

- the person's will and preferences must be given effect
- where the person's current will and preferences cannot be determined, the representative must give effect to what they believe the person's will and preferences are likely to be, based on all the information available
- if it is not possible to determine what the person would likely want, the representative must act to promote and uphold the person's personal and social wellbeing with the least possible restriction on their dignity and autonomy
- a representative may override the person's will and preferences only where necessary to prevent serious harm. In these circumstances, the representative must act to promote and uphold the person's personal and social wellbeing with the least possible restriction on their dignity and autonomy.

2.6. Tribunal proceedings and processes

It is important for a new supported decision-making framework in guardianship and administration legislation to be complemented by robust tribunal practices and processes that maximise the participation of people with disability in tribunal proceedings. Reform is also needed to public disclosure and confidentiality provisions to ensure the right balance is struck between transparency and privacy.

Maximising participation

It is essential people with disability can be heard and express their will and preferences in tribunal proceedings. However, people with disability and their families and supporters face barriers in participating in tribunal proceedings. For example:

- they are not always made aware of an application⁴⁷⁰
- there is a lack of accessible information about tribunal proceedings⁴⁷¹
- the manner in which the hearing is conducted, especially when it is via teleconference or online⁴⁷²
- the absence of adequate and culturally appropriate supports.⁴⁷³

We do not have evidence these kinds of barriers are characteristic of tribunals in all Australian jurisdictions. We can say however, that all tribunals should be conscious of the need to ensure, to the maximum extent feasible, that people with disability can participate meaningfully in proceedings that can have profound consequences for them.

Guidelines for Tribunals

In June 2019, AGAC released *Maximising the participation of the person in guardianship proceedings: Guidelines for Australian Tribunals (Guidelines for Tribunals)*.⁴⁷⁴ The *Guidelines for Tribunals* are not binding, but provide a model of best practice. They are designed to ensure the person with disability participates to the maximum extent feasible in:

- case management
- hearings on an application for a guardianship or administration order
- the review of an order.⁴⁷⁵

There are 26 guidelines in the *Guidelines for Tribunals*, covering all stages of the proceedings. These are contained in Appendix 6B.

These guidelines address many issues raised with the Royal Commission about the barriers people with disability face in participating in tribunal proceedings. This includes ensuring:

- steps are taken to ensure a person with disability is made aware of an application and upcoming hearing
- information is provided about available legal representation and advocacy support
- hearings do not proceed in the absence of the person with disability and without them being heard, other than in exceptional circumstances
- reasonable adjustments and adequate supports are available to people with disability to enable them to fully participate in hearings – for example, information and communications are accessible and adapted where necessary
- culturally accessible and responsible practices are used for First Nations and culturally and linguistically diverse people with disability.

Counsel Assisting submitted it was open to the Royal Commission to recommend the Australian Government and state and territory governments invest in and provide accessible and culturally appropriate information, guidance and training on supported decision-making to tribunal members, amongst others. Guidelines 16, 24 and 25 address training for members and register staff.

We recommend all state and territory tribunals consider adopting the *Guidelines for Tribunals* so that people with disability can participate in tribunal proceedings to the fullest extent.

In doing so, tribunals should review and update Guideline 15 to reflect any legislative reform made by each jurisdiction in response to our recommendations on a new supported decision-making framework (see Recommendations 6.4 to 6.10). Guidelines 8 and 9 should also be updated to align with any national approach adopted to collecting and publishing de-identified data on support and representation arrangements, in response to Recommendation 6.19.

The *Guidelines for Tribunals* could be incorporated in practice directions, specifying the procedures and practices the tribunal must follow. Some state and territory tribunals already have issued practice directions specifically relating to guardianship or administration lists.⁴⁷⁶

Where they do not already do so, we encourage tribunals to include in their annual reports the steps they are taking to adopt and meet the *Guidelines for Tribunals*.

Recommendation 6.11 Guidelines on maximising participation

- a. The Australian Guardianship and Administration Council should update the *Guidelines for Australian Tribunals: Maximising the participation of the Person in guardianship proceedings* to align with our recommendations on guardianship and supported decision-making (see in particular Recommendations 6.4–6.10 and 6.19).
- b. The guardianship division or list in each state and territory tribunal should consider adopting, through practice directions or other appropriate means, the updated *Guidelines for Australian Tribunals: Maximising the participation of the Person in guardianship proceedings*.

Public disclosure and confidentiality

Under guardianship and administration legislation in all states and territories, except the Australian Capital Territory, there are restrictions on disclosing or publishing personal information about people with disability who are subject to applications and orders for guardianship and administration.⁴⁷⁷

These provisions are referred to by terms such as, ‘confidentiality’, ‘non-disclosure’ orders or ‘gag laws’. Broadly speaking, people who exercise functions under guardianship and administration laws cannot disclose any personal information about a represented person they have obtained while discharging their functions. There are exceptions where they are authorised or required by law to do so and the represented person consents. These provisions also make it an offence for any person to publish or otherwise disseminate to the public any account of tribunal proceedings that identifies a party to the proceedings or associated persons, without leave of the tribunal.

The purpose of the confidentiality and non-disclosure provisions is protective. Guardianship and administration, and tribunal proceedings, involve private and personal information. Some people may be vulnerable and at risk of suffering harm if personal information about them, or the fact that they are subject to guardianship and administration applications and orders, is widely known.

The legislation in Victoria, Queensland and Western Australia provide for non-publication of the proceedings as the default position, but the tribunal may make a publication order if it considers it in the public interest to do so.⁴⁷⁸

Western Australia's submission following Public hearing 30 explained nothing in its legislation prevents a proposed represented person, or their family, from telling other people about guardianship and administration proceedings:

proposed represented persons, represented persons and others may speak publicly about their experiences in [guardianship] matters, but what they say cannot be reported in a way that identifies them.⁴⁷⁹

Witnesses gave evidence about these provisions effectively limiting the rights of a person with disability and their supporters talking publicly about their lives.⁴⁸⁰ The provisions create a risk that institutions such as hospitals, disability service providers, and public guardians and public trustees will be shielded from transparency and accountability because people cannot recount their experiences of tribunal proceedings.

Reform in Queensland

The *Guardianship and Administration Act 2000* (Qld) prohibits, without reasonable excuse, the publication of information about a guardianship proceeding if the publication is likely to lead to the identification of the relevant adult.⁴⁸¹ The prohibition applies to identification of adults concerned in the matter, regardless of whether the tribunal decides the adult has impaired capacity.⁴⁸² The tribunal may make an order authorising publication of information about a tribunal proceeding only where it is satisfied publication is in the public or the adult's interest.⁴⁸³

The Queensland Public Advocate recently released a report examining confidentiality in the guardianship system.⁴⁸⁴ This report focused in particular on the making of confidentiality orders by QCAT. It said the current provision (section 114A) 'disempowers the individual and arguably represents an outdated, paternalistic approach to this issue'.⁴⁸⁵ The report proposed a shift 'from the default position that people cannot speak about their guardianship experiences (in a personally identifying way) without tribunal authorisation, to the default position that they can'.⁴⁸⁶ The report recommended that the relevant provision be repealed,⁴⁸⁷ except where serious harm may be caused.⁴⁸⁸

Evidence presented at Public hearing 30 raised different views on the approach the Queensland Public Advocate proposed. The Queensland Public Guardian did not support a wholesale repeal of the relevant provision; rather, it supported an amendment that would allow people to consent to publication of their information but otherwise protect people from malicious disclosure of identifying information without their consent.⁴⁸⁹

Mr Dayne Kingsford from Queensland Advocacy for Inclusion supported the approach and said this would also strike the balance between privacy and rights, including dignity of risk.⁴⁹⁰ He said otherwise, the legislation could suggest that the person is not in control of deciding what is appropriate as public knowledge.⁴⁹¹

Recommended approach

We consider the default position under legislation should not be a prohibition on publication of material related to tribunal proceedings. Rather, the legislation should allow publication unless the tribunal makes an order preventing public identification of the person or their circumstances. The effect of this proposal is that the tribunal will need to be persuaded to exercise a discretion to prohibit publication, rather than starting with a presumption that publication should be prohibited. Ordinarily, the tribunal would be expected to give effect to the will and preferences of the party in the proceedings, thereby upholding that person's right to freedom of expression concerning their own affairs.

Recommendation 6.12 Public disclosure and confidentiality restrictions

States and territories should amend their guardianship and administration laws or tribunals acts to:

- repeal provisions prohibiting publication of material identifying a party to the proceedings as the default position
- empower the tribunal to make an order prohibiting publication of material identifying the party to the proceedings if the circumstances justify such an order, taking into account the will and preferences of that party.

2.7. Education and capacity building

We consider investment in education and capacity building activities is needed to improve understanding of supported decision-making.

Following Public hearing 30, Counsel Assisting submitted it was open to the Royal Commission to consider recommending that Australian, state and territory governments invest in and provide accessible and culturally appropriate information, guidance and training on supported decision-making to:

- those requiring supported decision-making
- supporters and representatives
- disability service providers, including employees and contractors of agencies who engage with people who require supported decision-making, their supporters and representatives
- judicial officers, tribunal members and the legal profession
- key government agencies – in particular the NDIA.⁴⁹²

We accept this submission. We consider public guardians or public advocates in each jurisdiction are best placed to lead efforts to provide information, guidance and training on supported decision-making. These efforts should be complemented by systemic advocacy.

A stronger role for public advocates and public guardians

Public advocates and public guardians have existing functions to provide information and undertake education activities, but these vary in scope and detail.⁴⁹³ Several law reform bodies have recommended public guardians or public advocates have primary responsibility for developing and delivering education programs about new guardianship legislation.⁴⁹⁴

We consider they should have a broad range of education functions for supported decision-making, similar to those specified in Victorian legislation,⁴⁹⁵ Queensland legislation⁴⁹⁶ and recommended by the NSWLRC.⁴⁹⁷ The functions should be broad enough to capture providing information and education about the new supported decision-framework following any legislative reforms (see Recommendations 6.4–6.10). The education function should not limit which groups the information or education can be provided to, but we propose key recipients should be identified.

We also recommend all public advocates and public guardians be empowered to provide advice and assistance to people who may require decision-making supports. Additional advice and assistance from a public advocate or public guardian can help remove or mitigate the barriers people with disability face in understanding and navigating legal processes.⁴⁹⁸

Our recommendation on the role of public advocates and public guardians to provide advice and assistance draws on the NSWLRC's report.⁴⁹⁹ The NSWLRC explained that a decision-making assistance and advice function is designed to reduce the need for formal assisted decision-making arrangements. It would also assist in ensuring that, if formal arrangements are required, the least restrictive option is taken.⁵⁰⁰

The function would enable public advocates and public guardians to assist people with decision-making arrangements, including applying to the tribunal for representation or support.⁵⁰¹ It would also allow a public advocate or public guardian to run an information and advice service about supported decision-making. The Victorian Public Advocate, for example, runs a service that provides information and advice about a range of topics, including supported decision-making, administration, guardianship and applications to VCAT.⁵⁰²

Each jurisdiction would need to consider further and define the circumstances in which its public guardian or public advocate could provide decision-making advice and assistance.

Appropriate and accessible information, education and training

In developing and delivering information, education and training programs on supported decision-making, we encourage the public advocates and public guardians to ensure information, education and training are grounded in the *CRPD* and the supported decision-making principles (see Recommendation 6.6).

Education and training for private representatives (present or prospective) in particular should emphasise the importance of Principle 4: Recognition of informal supporters and advocates and Principle 5: Access to support from our supported decision-making (see Recommendation 6.6).

It should encourage representatives to assist people, especially represented people in closed settings, to access advocates and informal supporters.

It is also important that information, education and training are produced and delivered in a variety of ways. This will maximise their accessibility and relevance to diverse audiences and communities, including First Nations and culturally and linguistically diverse communities. At Public hearing 30 several witnesses described a lack of appropriate and accessible information about guardianship and administration processes.⁵⁰³ Not all of information published by public guardians, public trustees or their equivalents is comprehensive or readily accessible. For example, the Queensland Public Trustee is still developing easy English material and does not produce material in languages other than English.⁵⁰⁴ However, it plans to incorporate more easy English in its new website.⁵⁰⁵

Recommendation 6.13 Information and education on supported decision-making

- a. States and territories should ensure that, where legislation to this effect is not already in place, the functions of public advocates and public guardians include providing information, education and training on supported decision-making to people requiring supported decision-making and their families, private supporters and representatives (present or prospective), disability service providers, public agencies, the judiciary, tribunal members and legal representatives.
- b. States and territories should ensure that, where legislation to this effect is not already in place, public advocates and public guardians are empowered to provide advice and assistance to people who may require decision-making support, including in relation to applications for support and representation orders.

Promoting supported decision-making through systemic advocacy

Systemic advocacy involves advocating for changes to legislation, policy and practice. It also has a role in safeguarding the rights and interests of people with disability.⁵⁰⁶ It can improve understanding and capacity-building on supported decision-making across relevant systems and processes. Systemic advocacy is discussed further in Chapter 3.

Some public advocates and public guardians have systemic advocacy functions.⁵⁰⁷ For example, the Victorian Public Advocate has functions to:

- promote the human rights of persons with a disability and the development of the ability of such persons to act independently⁵⁰⁸
- undertake advocacy for persons with a disability on a systemic or individual basis.⁵⁰⁹

The functions of the Queensland Public Advocate include:⁵¹⁰

- promoting and protecting the rights of adults with impaired capacity for a matter
- encouraging the development of programs to support ‘adults with impaired capacity for a matter’ to reach the greatest practicable degree of autonomy
- making reports to the Minister about relevant systemic matters.

However, as with the education functions of public advocates and public guardians, jurisdictions vary in the extent to which they have a public office charged with a systemic advocacy role on supported decision-making. For example, New South Wales and Tasmania do not have a public advocate, and their public guardians do not have a role in systemic advocacy. The Northern Territory does not have a public advocate, but the functions of its public guardian include ‘to advocate for adults with impaired decision-making capacity generally, including by promoting understanding and awareness of relevant issues’.⁵¹¹

Other organisations may have systemic advocacy functions relevant to supported decision-making. For example, the NSW Ageing and Disability Commissioner has functions ‘to inquire into and report on systemic issues relating to the ... promotion of the rights of adults with disability’.⁵¹² The NSW Ageing and Disability Commissioner is discussed in more detail in Volume 11, *Independent oversight and complaint mechanisms*.

Recommendation 6.14 aims to ensure that every state and territory has a body empowered to conduct systemic advocacy to promote supported decision-making. The elements of the recommendation draw on the functions contained in the *Guardianship and Administration Act 2019* (Vic) and *Guardianship and Administration Act 2000* (Qld), and recommendations made by the NSWLRC.⁵¹³

We do not specify which statutory body in each jurisdiction should undertake the systemic advocacy function. It is a matter for state and territory governments to decide which body – new or existing – is most suitable.

Recommendation 6.14 Systemic advocacy to promote supported decision-making

States and territories should ensure that, where this is not already the case, a statutory body has a function to undertake systemic advocacy to promote supported decision-making. This function should include:

- monitoring, investigating, researching, reporting, making recommendations and advising on any aspect of relevant decision-making legislation
- encouraging the development and improvement of programs, services and facilities that promote the autonomy of people with disability
- supporting organisations that undertake advocacy and education on supported decision-making.

Standards for public advocates, public guardians and public trustees

We consider improved guidance about supported decision-making is needed for public officials from the public advocate, public guardian or public trustee who can be appointed as representative decision-makers.

Guidance currently exists in the form of the National Standards of Public Guardianship and National Standards for Financial Managers, developed by AGAC. AGAC represents state and territory government agencies that have a role in ‘protecting adults in Australia who have a decision-making disability that impairs their capacity to make person or financial decisions’.⁵¹⁴ Their role covers all public guardians, public advocates and public trustees, along with guardianship tribunals, across Australia. AGAC aims to work towards a consistent approach to common issues, adopting a collaborative focus on relevant matters, and sharing information between agencies.⁵¹⁵

The National Standards of Public Guardianship were first introduced by AGAC’s members in 2001 and revised in 2009 and 2016. The National Standards for Financial Managers, which applies to public trustees, was last updated in August 2018. These follow from and closely relate to the National Standards of Public Guardianship.

These national standards do not have any legal basis or binding effect. However, they set out the ‘minimum expectations of staff when acting as legal decision makers on behalf of people with decision-making disabilities’.⁵¹⁶

The preamble of both sets of standards refer to the *CRPD*, in particular article 12. The National Standards of Public Guardianship also state that, in articulating key components of the role of public guardians in Australia, it draws on ALRC’s national decision-making principles.⁵¹⁷

The National Standards of Public Guardianship provide the following 10 standards:

6. Provide information
7. Support decision-making capacity
8. Ascertain will and preferences
9. Advocate
10. Protect
11. Make decisions
12. Record information
13. Participate in guardianship reviews
14. Promote professional development
15. Observe privacy and confidentiality requirements.

The National Standards of Financial Managers provide the following 12 standards:

1. Providing information
2. Advocating for the person
3. The person's views and involvement
4. Protecting assess
5. Making financial decisions
6. Investing money
7. Making payments
8. Recording information
9. Respecting privacy and confidentiality
10. Protecting and respecting legal rights
11. Being professional
12. Review of orders

We recommend updating the preambles of both national standards to include our recommended supported decision-making principles (see Recommendation 6.6). The supported decision-making principles build on and extend the ALRC's principles currently referenced in the National Standards of Public Guardianship.

We also recommend updating the national standards to align with any legislative reform state and territories undertake to introduce a new supported decision-making framework following our Recommendations 6.4 to 6.10. Amendments to the national standards discussed in this section and included in Recommendation 6.15 should not be delayed to coincide with legislative reforms.

We encourage public guardians, public advocates and public trustees to report on how they are meeting the National Standards of Public Guardianship and National Standards for Financial Managers in their annual reports, where this is not already the case.

Communications and meetings

At Public hearing 30 we heard about the frequency and nature of the communication between public guardians and public trustees and represented people. Witnesses gave evidence that they did not recall meeting their guardian or administrator face-to-face.⁵¹⁸ They also described the guardian or administrator failing to communicate with them, or their families, about important decisions.⁵¹⁹ Advocates told us in some instances it took 12 months for guardians to seek information about their clients after being appointed.⁵²⁰ We also heard evidence of guardians and administrators obstructing communications from family members, stopping people from seeing their family members and preventing family members from participating in decisions about them.⁵²¹

Public guardians and public trustees from Victoria, New South Wales and Queensland and the Public Advocate from Western Australia told us they aim to meet the people they represent within a certain period after being appointed.⁵²² They gave varying answers about whether personal, regular contact with the people they represent was required.⁵²³ The Public Guardians from Victoria and Queensland and the Public Advocate from Western Australia gave evidence that generally in-person meetings took place no more than once or twice a year.⁵²⁴ The WA Public Advocate accepted an annual visit would not give a guardian a clear understanding of how a person's capacity might fluctuate or change during the year.⁵²⁵

We accept resourcing constraints limit the extent to which public guardians and public trustees can visit represented people to get to know them and understand their will and preferences.⁵²⁶ But in our view this is what the general principles in guardianship and administration legislation require. It is also what public guardians acknowledge is necessary to make decisions consistent with the legislative requirements.⁵²⁷ It is not possible to make decisions that reflect the will and preferences of a represented person without regular and appropriate communications with that person.

The National Standards of Public Guardianship state:

- in Standard 3 'Ascertain will and preferences', that:

Guardianship staff making legal decisions, subject to the requirements of the legislation operating in the jurisdiction, will endeavour to ... meet in person or use audiovisual technology to have direct contact with the represented person at least once a year.⁵²⁸

- in Standard 1 'Providing information', that:

The financial manager has a duty to keep the person informed about all aspects of the management of the person's financial affairs, to the extent feasible and appropriate for the person.⁵²⁹

The National Standards for Financial Managers state:

- in Standard 3 'The person's views and involvement', that:

The financial manager will, to the extent appropriate, be in contact as regularly as practicable about major decisions that need to be made about the person's finances.⁵³⁰

- in Standard 11 'Being professional', that:

The financial manager will communicate with the person, where feasible and in ways the person can understand.⁵³¹

We consider stronger guidance is needed around communication and meetings in the national standards. The national standards should provide that communication and meetings between a represented person and the representative (that is, public officials from the public advocate, public guardian or public trustee who appointed as representative decision-makers) should be frequent, ongoing and directed to the purpose of getting to know the represented person and developing a trusted relationship.

Finally, meetings should take place, wherever practical, in line with a represented person's preferences. This may involve meeting in-person or having family members or other people from their support network attend the meeting.

Facilitating connections with advocates and informal supporters

Advocates and informal supporters can play an important role in supporting a proposed represented person and their family members in navigating the guardianship and administration system. For example, at Public hearing 30, Austyn gave evidence about how her neighbours supported her to better understand the guardianship process and what was required at the proceedings.⁵³² She said without the support of her neighbour she did not think she could understand the process.⁵³³

The availability of one or more appropriate decision supporters can also prevent people from being placed under guardianship or administration orders. Dr Pearce gave evidence that:

Guardianship would occur far less often if independent advocacy or supported decision-making services were widely available. Our experience is that represented persons are generally people with decision-making disability either without informal supporters (people like family or friends who are independent of paid service provision); or whose family or friends are experiencing conflict. Where a person is supported by family or advocates to make decisions for themselves, guardianship is unlikely to be necessary.⁵³⁴

The national standards include a standard on the role of guardians and financial managers themselves to advocate for the represented person.⁵³⁵ There is also some recognition in the national standards on acknowledging and respecting the role of people who provide decision-making support. This may mean, where appropriate, guardians and financial managers should consult with family members, carers and any other significant people chosen to provide support.⁵³⁶ However, advocates are not specifically mentioned, and guardians and financial managers are not required to facilitate connections with and access to advocates and informal supporters.

To help ensure represented people are under orders for the shortest possible time, public guardians and public trustees need to identify and facilitate connections with potential decision supporters. This may include connecting a represented person with a disability advocacy organisation or peer support program. This is in line with Principle 4: Recognition of informal supporters and advocates; and Principle 5: Access to support of our recommended supported decision-making principles (see Recommendation 6.6).

Cultural safety and responsiveness

Guardianship and administration services need to be provided in a culturally safe way for First Nations people and culturally and linguistically diverse people with disability.

Ms Alice Barter from Aboriginal Legal Service of Western Australia observed that guardianship and administration of First Nations people with disability can be viewed as another feature of the historical tendency of governments to seek to protect, but in fact to control, First Nations people. Ms Barter said it was important for public services, and public guardians, public trustees and administrators, to be conscious of the level of distrust First Nations people often have towards governments and public agencies. This distrust is compounded when guardianship and administration orders remove First Nations people's ability to exercise self-determination.⁵³⁷

We recognise that several public guardians and public trustees are taking steps to address the need for culturally appropriate engagement with First Nations and culturally and linguistically diverse people.⁵³⁸ For example, the NSW Public Guardian provides cultural awareness training, including Indigenous Cultural Competency Training, to guardianship staff.⁵³⁹ It also has in place a Community Visiting and Advocacy First Nations Community of Practice and the Murri Yarning Circle, where staff who identify as First Nations people are available to provide guidance and support on questions of culturally appropriate practice.⁵⁴⁰

In Victoria, the Public Advocate generally delegates her guardianship powers to a member of the action plan committee when the person under guardianship identifies as a First Nations person.⁵⁴¹ The Victorian State Trustees provide services to First Nations people through its Specialised Support Team. Over half of the Specialised Support Team staff have been trained in First Nations cultural responsiveness.⁵⁴² It is intended that all represented people who are recorded as First Nations people will be supported by the Specialised Support Team over coming months.⁵⁴³

We consider efforts to ensure culturally appropriate engagement can be bolstered and extended across all jurisdictions through recognition of its importance in the national standards. Neither the National Standards of Public Guardianship nor the National Standards for Financial Managers currently provide guidance on ensuring practices are culturally safe or responsive. They also do not refer to the need for staff to receive training on culturally appropriate practices.

We discuss cultural safety for First Nations people with disability in more detail in Volume 9.

Recommendation 6.15 Updating the national standards for public advocates, public guardians and public trustees

Public advocates, public guardians and public trustees, through the Australian Guardianship and Administration Council, should update the *National Standards of Public Guardianship* and *National Standards for Financial Managers* to:

- include the supported decision-making principles
- align with reforms to state and territory guardianship and administration legislation that give effect to Recommendations 6.4–6.10

- amend the relevant standards to provide that public officials acting as representatives should have frequent meetings and ongoing, accessible communication with the represented person to get to know the person and develop a trusted relationship. Meetings should take place in line with a represented person's preferences as to format and attendees, wherever practicable
- amend the relevant standards to recognise the importance of ensuring all engagement with First Nations and culturally and linguistically diverse people is culturally safe and responsive and that appropriate training for staff is provided to enable them to do so
- amend the relevant standards to recognise the importance of public officials acting as representatives facilitating connections between a represented person and advocates and informal supporters.

2.8. Financial decision-making

If I didn't have a disability I could have blown all my Centrelink payments the same day I got paid ... I have an intellectual disability and somehow that automatically meant that I wasn't capable of any financial decisions at all.⁵⁴⁴

The *CRPD* requires States Parties to take measures to ensure the equal right of people with disability to own and inherit property and to control their own financial affairs.⁵⁴⁵ However, issues about financial management, including abuse and exploitation, have been recurring themes throughout our work. These issues have frequently been associated with substitute decision-making.

Substitute decision-making about finances can happen informally in everyday situations. For example, a partner or family member of a person with disability may take control of their wages or dictate what is 'appropriate' to spend their money on.

Substitute decision-making on finances can also be formalised, including through administration orders, enduring powers of attorney, and NDIS or Centrelink nominee arrangements. Under financial management orders, a person has a private administrator, financial manager or public trustee appointed to manage their financial affairs, including making legally binding decisions. More people are affected by administration orders entrusting their financial affairs to public trustees than those affected by guardianship orders conferring decision-making authority on public guardians and their equivalents.⁵⁴⁶

Public trustees have been subjected to considerable scrutiny in recent years. Several jurisdictions have conducted public inquiries, recommending reform across a range of areas of public trustees' operation.⁵⁴⁷ In March 2022, the Australian Broadcasting Corporation's *Four Corners* aired a report criticising the operations of the Queensland Public Trustee.⁵⁴⁸ The Attorney-General of Queensland announced two investigations in response. These were an internal review of the Queensland Public Trustee's practices and policies, and an independent external review of the three cases highlighted in the *Four Corners* program.⁵⁴⁹

Public trustees are governed by legislation in each state and territory.⁵⁵⁰ They are also guided by non-binding National Standards for Financial Managers, developed and published by AGAC (see further discussion in section 2.7).⁵⁵¹ Public trustee officials are also bound by the ethical obligations that apply to public sector staff and other professional ethical duties and codes of conduct – for example, those that apply to tax accountants and lawyers.

Restrictions on autonomy in financial decision-making

I felt like all over again, decisions were made about my money without any consideration of what I wanted.⁵⁵²

At Public hearing 30, the Royal Commission heard evidence about how administration orders can:

- impact a person's confidence, self-esteem and sense of themselves⁵⁵³
- limit a person's ability to meet their daily needs and pursue interests⁵⁵⁴
- limit a person's ability to fulfil their right to culture, especially for First Nations people with disability⁵⁵⁵
- remove a person's choice of where and with whom they live.⁵⁵⁶

We also heard evidence about experiences that suggest financial mismanagement and conflicts of interest involving fees and decisions about financial matters.⁵⁵⁷

The decisions that are being made by the State Trustees affect me every day and in so many ways. It impacts my wellbeing, my access to day-to-day needs and my relationships too.⁵⁵⁸

Submissions have also described experiences of violence, abuse, neglect and exploitation in connection with financial decision-making. Experiences include financial abuse and mismanagement of funds by private administrators and public trustees.⁵⁵⁹ Submissions have described how public trustees have taken away all control over the day to day finances of people under administration orders and the negative impacts this has on their choice and control.⁵⁶⁰

Glenys*

Glenys is in her 40s. She is autistic and lives with dyslexia and a work-related injury.

A couple of years ago, she turned to a service provider for help.

'I went there for counselling, nothing more, but somehow I ended up in the public trustee system,' Glenys told the Royal Commission.

Glenys said the provider was the 'driving force' behind the move to have the public trustee appointed as her financial guardian. Glenys had no say in the matter and no-one informed her of the grounds for the decision. She said the public trustee ignored her human rights and unfairly presumed she was 'incapacitated' because of her disability.

'They never approached my family or friends about my capacity, or my doctors. They just made the decisions on a paper hearing without even a face-to-face meeting with me. Originally when the public trustee got control, they wanted to sell my assets including my house and put me into a group home. And then take over everything and my family wouldn't have any say on anything either.'

She'd spent years trying to 'overcome' her disability with education and training.

'Not to be put in mental, financial or psychological prisons ... This goes back to people's prejudice and internal values, not what's legally right for me.'

'They decided on my behalf to put me on disability benefit and the NDIS, when I wanted paid employment. They took me off further study plans that I had.'

Glenys explained the public trustee didn't pay her bills on time, incurring extra costs. Staff demonstrated 'coercive, controlling behaviours and unethical behaviour', Glenys said. There was no duty of care, 'extremely poor communication, a lack of transparency and no internal complaints system'.

Recently, she succeeded in having the trustee removed as financial administrator. Although she said initially it refused to relinquish control.

'I was flabbergasted when it sought a second and even a third order despite the evidence I had presented to the courts that I was capable of looking after all my own affairs.'

Glenys still has 'ongoing problems with the public trustee'. The agency is 'holding on' to her mortgage and banking details and is still on all Glenys's bills.

‘It looks like I’m not capable, so banks won’t deal with me directly. They just tell me to go away.’

Glenys said until the public trustee hands back her files, she is unable to engage with a disability employment provider.

‘It’s not their right to choose if I’m employable or not, but they’ve made those decisions and now I can’t re-enter the paid employment market and I’m stuck on volunteering. It’s turned my life upside down and I’d like to forget it altogether, but unfortunately, I’m still caught up in it. And there doesn’t seem to be any way out because no-one’s taking responsibility or accountability.’

Glenys wants to see ‘a conflict resolution system’ set up within public trustees.

‘So that court is not the only option. And an oversight body to keep public trustee systems honest and fair.’

Glenys said the service provider has never apologised.

‘So I presume they just don’t care. They should reflect on what the client’s needs really are and what is the person’s wishes and goals.’

Instead of empowering her, Glenys said the provider used ‘suppressive tactics’ to take her choices away. It gave evidence to a tribunal and excluded her ‘mentally, socially and emotionally’ from decisions concerning her.

**‘The decision-making power needs to be given back to us.
It’s about what we need and what we want, not what the
institution thinks we want.’**

* This is a de-identified narrative of an experience shared with us in a submission or private session. The person who shared their experience was not a witness. They did not give evidence, take an oath or give an affirmation. Nothing in this narrative represents a finding of the Royal Commission and any views expressed are those of the person, not of the Royal Commission.

Denial of dignity of risk and opportunities to practice financial decision-making

We heard evidence suggesting that a lack of opportunities to develop financial skills is linked with violence, abuse, neglect and exploitation of people under administration, and can reduce the likelihood that orders will be revoked.⁵⁶¹

At Public hearing 30, Mr Cartwright spoke about not being given a chance to build his financial literacy or budgeting skills under his administration order.⁵⁶² He said, 'I was apparently unable to have any responsibility, but no one showed me how to do things differently.'⁵⁶³ Mr Cartwright also said the annual financial statement he was given did not contain enough information to allow him to develop his knowledge and skills to manage his finances.⁵⁶⁴ He needed to personally seek out opportunities to build his financial decision-making skills to prove he no longer needed to be under administration orders.⁵⁶⁵

Financial skills development

We heard how a person can enhance their financial management skills by making their own decisions about money, with support as necessary. Mr Cartwright gave evidence about how making his own financial decisions keeps him focused.⁵⁶⁶ He has been able to pay his rent and bills on time and save some money.⁵⁶⁷

There's – there's – this is just an assumption that you can't learn anything and, because of that, they don't know where to start ... any [support to understand financial management] would be better than nothing.⁵⁶⁸

Financial independence programs

Some offices of the public trustees run programs to support people develop financial skills. This is a way to ensure that people under orders are given opportunities to practice financial decision-making.

In Queensland, for example, the Public Trustee offers the Steps to Financial Independence Pathway.⁵⁶⁹ This involves customers initially taking responsibility for one regular payment such as a bill, which may gradually increase to a number of payments.⁵⁷⁰ Customers are also referred to external financial literacy programs run by Money Matters, the Indigenous Consumer Assistance network and the Salvation Army, among others, to support them to manage their money.⁵⁷¹ The Queensland Public Trustee advised the Royal Commission that, for customers who are seeking to have their orders revoked after they complete the Financial Independence

Program (FIP), 'the Public Trustee assists them with gathering evidence required to complete an application for a Declaration of Capacity from QCAT'.⁵⁷² The FIP usually takes 12 months.⁵⁷³

Similarly in Victoria, the State Trustees offers a FIP⁵⁷⁴ to support people under administration to develop decision-making capability and take control of their finances. Under the program, consultants work with a person and their supporters to build capability and confidence to undertake financial management tasks. The FIP does not commence until the State Trustees have assessed all of the person's finances, and the person should be given at least six to 12 months on the program to ensure success. The consultants work with the person to establish what is important to them and then develop a plan to reach those goals, before encouraging them to control aspects of their finances.⁵⁷⁵ If successful, State Trustees will support participants to apply to VCAT for reassessment of their administration orders.⁵⁷⁶

The NSW Trustee and Guardian (NSW Trustee) has recently established a Customer Independence and Support team to 'develop the formal framework for supporting [financial management] clients where their circumstances are appropriate to receive support to increase their financial independence'.⁵⁷⁷ The Customer Independence and Support team will support people under orders who have been granted management of their estate, or part thereof, under section 71 of the *NSW Trustee and Guardian Act 2009* (NSW).⁵⁷⁸ Under section 71, the NSW Trustee may authorise a person it represents to manage all of their estate or as much of it as is considered appropriate.⁵⁷⁹ The team will identify people eligible for a section 71 authorisation and arrange an authorisation for them. After a person has successfully self-managed their finances under a section 71 authorisation for 12 months, the NSW Trustee will support them to seek a review of their financial management order.⁵⁸⁰

However, it appears that not all public trustees offer FIPs. This limits the options and opportunities people under administration orders have to develop their financial management skills.

Underutilisation of financial independence programs

Pathways into financial independence programs and similar programs include self-referral and referral by officers of the public trustee.⁵⁸¹ However FIPs may be underutilised. At Public hearing 30, Ms Josie Brown, the Executive General Manager of the Victorian State Trustees, said only 201 out of 9,256 people under administration orders appointing the State Trustee were participating in the FIP. She cited resourcing as a major reason for this low percentage⁵⁸² and explained that steps were being taken to inform more people under orders about the program.⁵⁸³ Similarly, the Queensland Public Trustee's statement to the Royal Commission states, as of 31 October 2022, only 78 customers were participating in the FIP.⁵⁸⁴

Operation of financial independence programs

There appears to be scope for improvement in the operation of existing FIPs. Mr O'Donnell told us he really wanted to do the FIP, but he found it difficult initially to get information about the program.⁵⁸⁵ Mr Cartwright raised concerns with his proposed FIP agreement, including that the program did not provide him with enough responsibility to build his financial capabilities.⁵⁸⁶ The State Trustees acknowledged the process for finalising Mr Cartwright's FIP agreement was 'unduly drawn out' and 'the time taken to include Mr Cartwright on the FIP was not in his best interest'.⁵⁸⁷

Past reports have also highlighted shortcomings in the design and implementation of FIPs. These shortcomings may mean they cannot be used effectively as a pathway out of administration orders. For example, the Victorian Ombudsman review of the Victorian State Trustee identified a number of issues with the FIP, including that:

- few represented people get an opportunity to participate in the program⁵⁸⁸
- the program does not include the provision of advice or support to build people's financial skills⁵⁸⁹
- the program does not involve partnering with other support services that could help people build their skills⁵⁹⁰
- the administrative burden of identifying and placing a person onto the program is a disincentive for staff⁵⁹¹
- even when a person manages their expenses successfully, the State Trustee does not proactively recommend that VCAT alter or revoke the administration order.⁵⁹²

The review said that evidence before it 'raised doubts about the program's effectiveness in building clients' independence'.⁵⁹³ It recommended that the State Trustees '[w]ork with financial counselling and community support organisations to develop an effective program to build clients' financial skills and capacity to manage their financial affairs independently'.⁵⁹⁴

Establishing and strengthening independence programs

At Public hearing 30, Mr O'Donnell made a number of recommendations for change, including:

- the State Trustees should provide practical assistance to help people with disability achieve their financial goals⁵⁹⁵
- people with disability should be given the opportunity to build on their skills so they can be more independent with their money.⁵⁹⁶

Recommendation 6.16 seeks to achieve these aims by establishing or improving financial skills development programs so they are available to all people under representation orders that appoint the public trustee as the representative. Since many people under administration orders could benefit from participation in financial skills development programs, there would be merit in extending the programs over time to all people under administration orders.

We recommend that programs should be developed in partnership with representative organisations of people with disability, particularly people with cognitive impairment, and with financial counselling or community support organisations. This proposal draws on the Victorian Ombudsman's recommendation that an element of co-design with people with disability be built in. The Victorian Ombudsman recommended:

If the government chooses to retain State Trustees' status as a state-owned company, consider the following skills and experience when recommending State Trustees board members for appointment – lived experience of disability and mental illness, and experience as a carer or advocate.⁵⁹⁷

The focus on eligibility recognises the low uptake of current programs and aims to create a broader base of suitable participants. Currently, Victoria requires people to be 'relatively settled' before they can participate in the FIP.⁵⁹⁸ In Queensland a person must be on a full administration order, meaning a plenary order, to be eligible. It is also 'highly desirable' that they have a support network.⁵⁹⁹ The requirement to proactively promote programs also addresses the current low uptake.

Our recommendation is designed to provide pathways out of administration orders by providing review rights for people who are not accepted into programs and supporting people to apply for variation or revocation of orders when they successfully complete their program. In its submission to the review by the Victorian Ombudsman, Victorian Legal Aid recommended that 'State Trustees adopts an internal policy that it applies for revocation of an order once the FIP has been successfully completed'.⁶⁰⁰ We have drawn on this recommendation, but we propose that the applicant for revocation should be the person under administration, with support and information from the State Trustee as appropriate.

The recommendation requires annual reporting on programs to provide an element of accountability through public and parliamentary scrutiny. Again, this element draws on the Victorian Legal Aid submission to the Victorian Ombudsman review. The submission recommended the 'State Trustees adopts incentives to assist people to build their capacity (for example KPIs for supporting represented people to transition on to the FIP)'.⁶⁰¹ Our recommendation goes further, requiring public trustees publicly report on the performance of financial skills programs rather than merely measuring and recording this internally.

Recommendation 6.16 Financial skills development programs

- a. All public trustees should offer a financial skills development program to people under a representation order appointing the public trustee as a representative. The program should promote financial independence and:
 - be developed in partnership with representative organisations of people with disability, including organisations representing people with intellectual disability, and financial counselling community support organisations

- incorporate broad eligibility criteria
 - be actively promoted, especially among people entering administration.
- b. Upon successful completion of the program, public trustees should support a person to apply for a review of their order. If a person is not eligible for the program, the public trustee must advise them of their right to apply to the relevant tribunal for review of their order.
 - c. Public trustees should report annually on the number of people who have participated in the program, the number who have completed it and the number who have subsequently transitioned out of administration arrangements.

Public trustee fees and charges

People who have the public trustee appointed through administration orders may be required to pay fees and charges, even though they did not choose the services of the public trustee.⁶⁰² These fees can be substantial. A person under an administration order may also not be aware that they are required to pay, or are paying, fees and charges to the public trustee. Even after they become aware, they may be unsure of the amounts they are liable for or they may find it difficult to obtain accessible information about the public trustee's fees and charges.

Recent reviews have considered the fees and charges payable to public trustees.⁶⁰³ These reviews have found:

- complexity in fees and charges,⁶⁰⁴ including the criteria for hardship fee relief⁶⁰⁵
- a lack of transparency about fees and the policies guiding how and when they are charged⁶⁰⁶
- a lack of clarity about the services people under administration orders receive for their fees⁶⁰⁷
- unreasonable fees and charges⁶⁰⁸ – for example, fees and charges unrelated to work actually performed⁶⁰⁹
- the potential for a trustee's fees, charges and revenue-earning arrangements to breach its fiduciary duties⁶¹⁰ and even to constitute a betrayal of trust⁶¹¹
- elements of monopoly pricing by the trustee for people under administration orders.⁶¹²

Overall, the fee structures and arrangements of public trustees are complex. Public trustees have a number of functions, each of which may incur a flat fee, hourly rate, annual fee, commissions, additional costs, or a combination of these. In particular, fees and charges vary across jurisdictions.

Public trustees have discretion to reduce or waive fees for people under certain circumstances, including financial hardship or the existence of a financial management order. The extent to which fee relief occurs varies across jurisdictions and is not always readily apparent from publicly available material, such as annual reports.

Transparency of fees and charges

The 'lack of transparency about the use of a person's resources for administration and litigation' was an issue raised in Public hearing 30.⁶¹³ We heard evidence that people under administration orders may not be aware they are paying fees to the public trustee. For example, Anthony told the Royal Commission he 'was not informed of any fees or anything associated' in for Killara's administration order.⁶¹⁴ Mr Cartwright said he found out he was charged fees only recently, when his lawyer and support worker advised him of the fact.⁶¹⁵

Queensland Advocacy for Inclusion gave a similar account describing the situation of 'Julia' – a recipient of an age pension who was concerned about the fees charged by the Queensland Public Trustee. Julia was charged fees which amounted to over 25 per cent of her monthly benefit. When Julie raised concerns with the Queensland Public Trustee, she was told she was entitled to a hardship rebate, but this was not consistently applied to her account.⁶¹⁶

The Queensland Public Advocate's 2021 review notes 'the Public Trustee has adopted a particularly conservative approach to providing information to clients and their supporters'. It also comments extensively on the 'historical practice of the Public Trustee to not publish its policies, procedures and manuals that guide decisions about when and why fees are charged'.⁶¹⁷ The Queensland Public Advocate recommended improving the transparency of the Queensland Public Trustees' fees and charges by:⁶¹⁸

- providing clear and accessible information to people under administration orders about fees and charges and the services people will receive for those fees
- publishing policies and manuals that guide what services people under administration orders receive and how the fees and charges for those services are calculated and applied, in accessible language and format
- on appointment, annually and after any significant change to the person's financial circumstances, sending personal correspondence to each person under an administration order detailing the services they will receive and the fees for those services
- reviewing policies and practices to ensure staff are actively encouraged to be responsive to people and their supporters, particularly on explaining fees and charges
- presenting information in people's statements of accounts in a more transparent and understandable manner.

During the Queensland Public Advocate's review, the Public Trustee began 'actively improving the quality and detail of information about its fees and charges on its website and in other publications'.⁶¹⁹ Following the review, the Public Trustee accepted the Public Advocate's recommendation in full and has taken steps such as developing a 'ready reckoner' to explain fees and charges in plain language.⁶²⁰

Other public trustees have taken steps to enhance communication with represented people and improve the transparency of fees and charges. Following their first meeting with the Victorian State Trustees, people are given a 'Welcome Pack' which includes a copy of a brochure called 'Commissions, Fees & Charges VCAT Appointments'.⁶²¹ State Trustees engaged the organisation Information Access Group to assist convert the brochure into plain English. They plan to review the 'Welcome Pack' before June 2023 and 'survey various user groups to ensure required needs are appropriately identified and met' in subsequent versions of relevant documents.⁶²²

Nonetheless, Public hearing 30 showed there is still scope for improvement in how some public trustees communicate with people under administration orders. The Queensland Public Trustee's submission in Public hearing 30 stated following an independent review of its fees and charges, it has taken a 'targeted effort' to make its fees 'less complex to enable customers, their support networks and other stakeholders to more easily understand' its fee structure.⁶²³

Recommendation 6.17 aims to increase the transparency of public trustee fees and charges across the states and territories, reflecting aspects of the Queensland Public Advocate's recommendation to this effect. Recommendation 6.15, on the revision and application of the National Standards for Financial Managers, addresses the related issues of staff communication with people under administration orders and accessible information.

Recommendation 6.17 Transparency of public trustee fees and charges

Public trustees in each state and territory should:

- publish accessible information about the services they provide to people under administration orders, the fees and charges applicable for those services and the ways in which fees are calculated for each individual
- on appointment, annually and following any significant change to a person's circumstances, send to people under administration orders individualised and accessible information detailing the services they will receive and the fees for those services.

Fairness of fees and charges

At Public hearing 30, Mr O'Donnell spoke about the State Trustee charging him for its services by taking a percentage of his Centrelink payments. He was unhappy about having to pay for a service he thought was unsatisfactory.⁶²⁴ Ms Nunn gave evidence about the monthly 'administration fees, asset management fees, other miscellaneous fees' that her brother Johnno had to pay under administration. These equated to about \$600, but Johnno was eligible for a rebate of around \$500 to subsidise the costs of his administration. However, he then received an inheritance, which made him ineligible for the rebate. Johnno's fees increased to around \$600 a month, which Ms Nunn described as 'a huge hit on his disability pension'.⁶²⁵

Past reviews and inquiries have considered the appropriateness and equitability of public trustees' fees and charges. The Victorian Ombudsman considered the Victorian State Trustees' fees and commissions. It noted 'People who complain to the Ombudsman about State Trustees often mention the amount State Trustees charges for its services.'⁶²⁶ Its report concluded that '[o]ther public trustees have more generous hardship policies for clients with low income or assets'.⁶²⁷ It also discussed other concerns about fees and charges, including that it can take some time for represented people to have fees reimbursed under the State Trustees' fee relief scheme⁶²⁸ and that the discretion to waive fees is rarely exercised.⁶²⁹

The Western Australian Office of the Auditor General's report, *Public trustee's administration of trusts and deceased estates*, considered the appropriateness and transparency of the Western Australian Public Trustee's self-funding fee model. It recommended the Department of Treasury conduct a review to consider whether services provided to those with limited financial means should be funded by government, rather than – as is currently the case – subsidised by fees charged to other clients, who may not be aware of the subsidy.⁶³⁰ As at time of writing, the review has commenced.⁶³¹

The Independent Review of the Public Trustee in Tasmania considered a range of issues relating to fees and conducted a comparison of the fees that a represented person is charged across jurisdictions.⁶³² It recommended:

The Treasurer request the Tasmanian Economic Regulator to undertake a review of the Public Trustee's fees and charges for those clients who are required by legislation to use its services.⁶³³

Similarly, the Queensland Public Advocate recommended a full review of the fees and charges regime for people under administration, to achieve greater simplicity, equity and autonomy.⁶³⁴ In response, the Queensland Public Trustee engaged PricewaterhouseCoopers (PwC) to conduct an independent and comprehensive review of its fees and charges.⁶³⁵

The *Review of fees and charges: Public Trustee of Queensland* (the PwC report) was published on 24 June 2022. This report presented five 'charging model concepts' or possible approaches to fees, along a scale with more equitable approaches towards one end and more transparent approaches at the other.⁶³⁶ The PwC report considers which charging model is most suitable for each of the services the Queensland Public Trustee provides and recommends a model for each.⁶³⁷ The recommended model for financial management services is to retain the existing approach to charging but 're-base rates and thresholds (where applicable), to realign expected cost recovery to contemporary policy and targets'.⁶³⁸ The practical implications of this include discontinuing some fees, simplifying others and adjusting the threshold for calculating certain charges.⁶³⁹ Indicative pricing, according to the recommended model, is estimated to improve affordability substantially for people requiring the highest levels of support from the Public Trustee, while the cost for other people receiving services from the Public Trustee would slightly increase.⁶⁴⁰

The Queensland Public Trustee's response to Counsel Assisting submissions for Public hearing 30 referred to the PwC report. The response noted that approximately 80 per cent of people under administration by the Public Trustee receive 'some form of discounted fees'.⁶⁴¹ It further submitted the 'financial management service has operated consistently and significantly below cost recovery levels' and people under financial management with the greatest financial need are eligible for both 'Community Service Obligation' rebates and discretionary 'hardship' rebates.⁶⁴² The response did not say whether the charging models recommended by PwC have been accepted.

Recommendation 6.18 Review of public trustees' fees and charges

State and territory governments should ensure that public trustees' fees and charges have been independently reviewed since 2019. Where such a review has not been conducted since this time, state and territory governments should arrange a comprehensive review of the fees and charges payable by people under administration orders to the public trustee in their jurisdiction. The reviews should make recommendations to ensure fees and charges are fair and equitable for all people under administration orders.

2.9. Data collection and reporting

The AGAC, tribunals, public guardians and public trustees publish data on the number of guardianship and administration orders across each jurisdiction. However, the data is neither collected nor presented in a uniform way. Furthermore, there is limited and inconsistent publicly available data on:

- the duration of orders
- the types of disability people under orders experience
- demographic factors, such as the age, cultural and linguistic diversity, and First Nations status of people under orders
- whether people under orders are NDIS participants.

In general, there is less data available on administration orders and the people who are subject to them, compared with guardianship orders. Data on guardianship and administration has been discussed in section 2.3.

AGAC has also acknowledged the lack of reliable data on the participation rates of people subject to an order or review of an order in guardianship or administration proceedings.⁶⁴³ The *Guidelines for Australian Tribunals: Maximising the participation of the Person in guardianship proceedings* include a guideline on the collection and reporting of data on participation rates at hearings and related matters.⁶⁴⁴ We endorsed these guidelines in Recommendation 6.11. Data on participation rates is also referred to in Recommendation 6.19 below.

AGAC collates and publishes disaggregated data on people under guardianship and administration orders.⁶⁴⁵ However, this data is not comprehensive. AGAC said it receives no funding to collate and publish its annual overview of statistics. Also, it does not have powers to require relevant bodies to collect or provide data.⁶⁴⁶

Data is collected by public guardians and public trustees, as well as tribunals, but this too is neither consistent nor complete.⁶⁴⁷ Counsel Assisting submitted it is open to the Royal Commission to consider recommendation that:

each Australian, state and territory governments develop and agree on the collection and publication of de-identified data, including consistent definitions and consistent collections, to enable reporting on trends and comparison of data collections.⁶⁴⁸

In its response to Counsel Assisting submissions, the Western Australia Government expressed in-principle support for this proposal.⁶⁴⁹ The Australian Government's response identified initiatives, including the National Disability Data Asset being developed with state and territory governments and the Data Sharing Agreements the NDIA is making with each state and territory.⁶⁵⁰ Despite these developments, we consider there is still a need for a centralised and uniform approach to the collection and publication of data on representation and support arrangements. We discuss this further in Volume 12.

Recommendation 6.19 provides the basis for a national approach to data on representation and support. The consistent collection and regular publication of robust data is necessary to provide an evidentiary basis for further reforms in this area. Systematic data collection can reveal important trends such as:

- the extent to which representation and support arrangements are linked with NDIS participation
- any shifts towards or away from support arrangements for people under representation orders, including administration orders
- the changing demographics of people subject to representation and support arrangements.

In our view, the Australian Institute of Health and Welfare (AIHW), Australia's leading health and welfare statistics agency, is the most appropriate body to collect and publish de-identified data on support and representation agreements. The AIHW's primary focus is 'on collation and reporting of data collected as a by-product of activities that occur in the process of delivering services (administrative data)'.⁶⁵¹

The AIHW is also well placed to play the collaborative role needed for this recommendation.⁶⁵² The AIHW advised the Royal Commission that its:

legislated role is to work with others to develop data standards and collections across health and welfare, and to publish statistics across these areas. It works closely with governments – including Commonwealth, state and territory authorities with health and welfare responsibilities, the Australian Bureau of Statistics (ABS) and other statistical agencies – and with the academic and non-government sector to make this happen.⁶⁵³

The AIHW collects data on many aspects of the lives of people with disability and produces an annual *People with disability in Australia report*.⁶⁵⁴ We consider this report further in Volume 12.

The Australian Government's response to Counsel Assisting submissions for Public hearing 30 raised a number of factors that the Australian Government and each state and territory government would need to consider in implementing the recommendation below, including:

- how a suitable governance body to support changes across jurisdictions and to identify technical barriers can be identified
- which collection and processing methods ought to be used and how appropriate of those methods are to the service population and to service providers
- how to use identified data in cases to support data linkage for the creation of aggregate de-identified statistics.⁶⁵⁵

We agree. We also refer to Volume 12 which includes a recommendation for a strategy to extend disability data collection, including to improve data on types of impairment and data for intersectional analysis.

Recommendation 6.19 Data collection on support and representation arrangements

The Australian Government and states and territories should develop and implement a national approach to collecting and publishing de-identified data on support and representation arrangements, led by the Australian Institute of Health and Welfare.

The national approach should consistently use definitions of 'disability', 'representation' and 'support' arrangements proposed in this *Final report*, and should employ methodologies which enable reporting on comparisons across jurisdictions and trends over time.

The national approach should include collection and publication of data on:

- numbers of formally appointed representatives and supporters, disaggregated appropriately
- the extent to which people with disability who are the subject of the proceedings participate in the proceedings and the manner in which they participate (for example, in person or via alternative technological means)
- numbers of representative agreements commenced, terminated, revoked, varied or reviewed
- the extent to which people with disability who are the subject of the proceedings are legally represented.

The data should identify, to the greatest extent practicable, types of impairment, age, First Nations people with disability, culturally and linguistically diverse people with disability, LGBTIQ+ people with disability, women with disability and National Disability Insurance Scheme participants.

2.10. Complementary reform

NDIS and disability service providers

The Australian Government recognises for some people with disability and their supporters the NDIS is complex to navigate.⁶⁵⁶ The NDIS has contributed to an increase in guardianship and administration orders (see Section 2.3).

The Australian Government submitted the NDIS Supported Decision-Making Policy is intended to improve the way people with disability are supported to make decisions in the NDIS. The expectation is the need for substitute decision-making, whether through nominees or public guardians, will be reduced.⁶⁵⁷ The Implementation Plan for the policy calls for the NDIA to develop and promote resources to increase the opportunity for participants to make decisions and exercise choice and control. This involves developing training and resources about supported decision-making in the NDIS for participants, providers, the sector and community.⁶⁵⁸

Service providers also need more information, guidance and training on supported decision-making to improve the way the way people with disability are supported to make decisions about day to day matters and arrangements for the delivery of disability services. We discuss this further in Volume 10.

Resourcing implications

Several witnesses identified the need for adequate funding for supported decision-making initiatives to reduce reliance on guardianship and substitute decision-making arrangements.⁶⁵⁹ We have heard how current funding and resources provided to offices of the public advocate, guardian and trustee are not adequate to fulfil their statutory obligations.⁶⁶⁰ Ms Smith said that resourcing constraints often prevented the Queensland Public Guardian from taking active steps to apply for the revocation of orders where this is appropriate.⁶⁶¹ Similarly, Dr Pearce, the Victorian Public Advocate, explained the increased resource implications to give effect to a person's will and preference and the crucial need to fund a supported decision-making model to enable implementation and reduce guardianship.⁶⁶²

Guardianship applications and orders increased between 2017–18 and 2020–21 (see section 2.3). In its annual report for 2021–22, QCAT commented this increase in their workload 'has not been met with a corresponding increase in resources to support decision-makers and to try to cope with the demand'.⁶⁶³

Past reports and reviews into guardianship and administration have also considered the need for additional resources and funding.⁶⁶⁴ The NSWLRC recognised the resourcing implications of its recommendations. However, it suggested the investment involved in implementing these recommendations should reduce the need to resort to representation orders. This should reduce resourcing pressures.⁶⁶⁵

The NSW Government and QCAT both raised concerns about resourcing and funding for recommendations proposed in Counsel Assisting's submissions.⁶⁶⁶ The NSW Government advised the recommendations, if adopted, will likely have significant financial impacts.⁶⁶⁷ QCAT suggested recommendations for funding should accompany Counsel Assisting's recommendations. They said if this is absent 'recommendations with resource implications will not be able to be seriously considered or implemented'.⁶⁶⁸

We acknowledge our recommendations will require financial support from governments. We encourage governments to dedicate sufficient, ongoing funds to their implementation, recognising that respecting the autonomy of people with disability is critical to the prevention of violence, abuse, neglect and exploitation.

In particular, public advocates, guardians and trustees will require sufficient funding to improve their practices as we recommend. These include:

- fulfilling the broad education functions we recommend (see Recommendation 6.13)
- improving the quality and frequency contact they have with people they represent (see Recommendation 6.15).

Public guardians and public advocates would need to develop implementation plans for the relevant state and territory governments to consider for the purpose of allocating additional funds in light of Recommendations 6.13 and 6.15.

Reforming other laws and systems that allow for substitute decision-making

Finally, our recommendations are intended to provide a model for further reform in other areas which permit substitute decision-making. This includes enduring powers of attorney and advance care directives, Centrelink and NDIS nominee arrangements, and laws on medical consent and mental health.

This process should begin with implementing the second aspect of Recommendation 6.6, reviewing and reforming other laws concerning individual decision-making to give legislative effect to the supported decision-making principles.

2.11. Australia's interpretative declaration

As discussed in section 2.2, Australia has made an interpretative declaration outlining its understanding that article 12 of the *CRPD* allows for 'fully supported or substituted decision-making arrangements, which provide for decisions to be made on behalf of a person, only where such arrangements are necessary, as a last resort and subject to safeguards'.⁶⁶⁹ The interpretative declaration does not change the legal effect of the article or Australia's obligations under the *CRPD*.

At Public hearing 18, 'The human rights of people with disability and making the Convention on the Rights of Persons with Disabilities a reality in Australian law, policies and practices', we heard evidence from Ms Suzanne Robertson, the First Assistant Secretary of the Attorney-General's Department with responsibility for the Office of International Law. Ms Robertson said the reason for the interpretative declaration was to transparently present the Australian Government's view that article 12(3), read with article 12(4), 'does not prevent substitute decision-making in all circumstances'.⁶⁷⁰ Ms Robertson said:

whilst issues of legal capacity and autonomy of decision-making must be the first point of call, there will be circumstances in which people require support of various levels to exercise their rights and the text of the Treaty, we say, does not prevent that from occurring.⁶⁷¹

When questioned about the continued utility of the interpretative declaration, Ms Robertson said:

Until policy changes, [the declaration is necessary for] some of the most extreme and difficult examples that you could talk about in this area.⁶⁷²

In both its 2013 and 2019 Concluding Observations on Australia's compliance with the *CRPD*, the *CRPD* Committee recommended the Australian Government review the interpretative Declaration with a view to withdrawing it.⁶⁷³ The Australian Human Rights Commission (AHRC) and civil society organisations have also consistently recommended Australia withdraw the interpretative declaration.⁶⁷⁴ The AHRC said the interpretative declaration is 'a significant barrier to the necessary reform of law, policy and practice'.⁶⁷⁵ Some witnesses also expressed this view.⁶⁷⁶ Submissions have also raised concerns about the interpretative declaration.⁶⁷⁷

Ms Rosemary Kayess and Therese Sands, in their research report *Convention on the Rights of Persons with Disabilities: Shining a light on social transformation*, argue the interpretative declaration restricts implementation of the *CRPD* and prevents reform. They suggest the interpretative declaration is a mechanism to 'support the legal, policy and practice framework underpinned by ableism and these tools enable violence, abuse, neglect and exploitation'.⁶⁷⁸

Although the ALRC report did not consider it necessary to recommend withdrawal of the interpretative declaration, it concluded:

there is an opportunity to send a clear message and to provide conceptual clarity in place of any confusion, or negative messaging, arising out of the Interpretative Declaration. If the Declaration remains as it is, or without further explanation, it may be seen to create ‘a sense of complacency’; and may ‘substantially diminish Australia’s progress in disability rights and undermine its position as a State committed to advancing the inclusion, participation and wellbeing of people with disabilities, in our country and overseas’.⁶⁷⁹

At Public hearing 30, Dr Bennett from the NDIA said he did not consider the interpretive declaration creates impediments for the NDIA in working to the objectives of the *NDIS Act*.⁶⁸⁰ At the time of Public hearing 18, the Australian Government said it had no intention of withdrawing the interpretative declaration.⁶⁸¹

All Commissioners agree that, if the Royal Commission’s recommendations are implemented, Australia will be moving towards compliance with article 12 of the *CRPD*. Commissioners take different views on whether the interpretative declaration needs to be withdrawn.

Withdrawing the interpretative declaration

The Chair and Commissioner Ryan’s view is that the interpretative declaration is consistent with both the language of article 12 and the principles and recommendations addressed in this chapter. They believe that the interpretive declaration does not create a significant barrier to the necessary reform of law, policy and practice. In particular, the interpretive declaration is not an impediment to the acceptance in legislation and practice of supported decision-making. Accordingly, the Chair considers a persuasive case has not been made for withdrawal of the interpretative declaration. Commissioner Ryan does not believe that a persuasive case has been made for retaining or withdrawing it.

Commissioners Bennett, Galbally, Mason and McEwin consider the Australian Government should withdraw the interpretative declaration. These four Commissioners consider withdrawal of the interpretative declaration will have a strong symbolic impact and centre a human rights-focus in the shift towards supported decision-making in Australia. They consider it will promote legal, policy and practice reform by focussing attention on a principled approach to supported decision-making and the need to centre the human rights of people with disability. It will also act as further incentive to implement our recommendations and move away from current systems which deny the autonomy of people with disability. They therefore recommend the withdrawal of this interpretative declaration.

Recommendation 6.20 Interpretative declaration

Commissioners Bennett, Galbally, Mason and McEwin recommend the Australian Government withdraw its interpretative declaration in relation to article 12 of the *Convention on the Rights of Persons with Disabilities*.

Endnotes

- 1 Transcript, Alastair McEwin (Commissioner), Public hearing 1, 16 September 2019, P-16 [8–13].
- 2 *Letters Patent* (Cth), 4 April 2019 (as amended), recitals.
- 3 See: *Convention on the Rights of Persons with Disabilities*, opened for signature 30 March 2007, 2515 UNTS 3 (entered into force 3 May 2008), preamble, para (n) and art 3(a).
- 4 Christine Bigby, Terry Carney, Shih-Ning Then, Ilan Wiesel, Craig Sinclair, Jacinta Douglas & Julia Duffy, Living with Disability Research Centre, *Diversity, dignity, equity and best practice: a framework for supported decision-making*, Report prepared for the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, January 2023.
- 5 ‘Roundtables’, *Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability*, web page. <disability.royalcommission.gov.au/policy-and-research/roundtables>
- 6 Transcript, Beth Walker, Public hearing 25, 12 July 2022, P-106 [43] –P-107 [3].
- 7 Transcript, Kate Eastman (Counsel Assisting), Public hearing 30, 21 November 2022, P-11 [1–3].
- 8 Australian Law Reform Commission, *Equality, capacity and disability in Commonwealth laws*, Final report, ALRC report 124, August 2014, pp 119–23; Christine Bigby, Terry Carney, Shih-Ning Then, Ilan Wiesel, Craig Sinclair, Jacinta Douglas & Julia Duffy, Living with Disability Research Centre, *Diversity, dignity, equity and best practice: a framework for supported decision-making*, Report prepared for the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, January 2023, p 6.
- 9 Transcript, Justine O’Neill, Public hearing 4, 18 February 2020, P-30 [1–4].
- 10 *Convention on the Rights of Persons with Disabilities*, opened for signature 30 March 2007, 2515 UNTS 3 (entered into force 3 May 2008), art 12.
- 11 Shih-Ning Then, Terry Carney, Christine Bigby, Ilan Wiesel, Elizabeth Smith & Jacinta Douglas, ‘Moving from support for decision-making to substitute decision-making: legal frameworks and perspectives of supporters of adults with intellectual disabilities’, (2022), vol 37 (3), *Law in Context*, pp 139–40.
- 12 Committee on the Rights of Persons with Disabilities, *General comment no. 1 (2014) Article 12: Equal recognition before the law*, UN CRPD/C/GC/1, (11 April 2014), [17].
- 13 Christine Bigby, Terry Carney, Shih-Ning Then, Ilan Wiesel, Craig Sinclair, Jacinta Douglas & Julia Duffy, Living with Disability Research Centre, *Diversity, dignity, equity and best practice: A framework for supported decision-making*, Report prepared for the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, January 2023, p 31.
- 14 Christine Bigby, Terry Carney, Shih-Ning Then, Ilan Wiesel, Craig Sinclair, Jacinta Douglas & Julia Duffy, Living with Disability Research Centre, *Diversity, dignity, equity and best practice: a framework for supported decision-making*, Report prepared for the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, January 2023, p 2.
- 15 See for example Exhibit 30-114, ‘Statement of Austyn’, 8 November 2022, at [49–50]; Transcript, AAI, Public hearing 3, 2 December 2019, P-31 [20–27].
- 16 Committee on the Rights of Persons with Disabilities, *General comment no. 1 (2014) Article 12: Equal recognition before the law*, UN CRPD/C/GC/1, (11 April 2014), [27].
- 17 Christine Bigby, Terry Carney, Shih-Ning Then, Ilan Wiesel, Craig Sinclair, Jacinta Douglas & Julia Duffy, Living with Disability Research Centre, *Diversity, dignity, equity and best practice: a framework for supported decision-making*, Report prepared for the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, January 2023, Appendix A, p 175.
- 18 Committee on the Rights of Persons with Disabilities, *General comment no. 1 (2014) Article 12: Equal recognition before the law*, 16th sess, UN CRPD/C/GC/1 (11 April 2014), [9].
- 19 Transcript, AAI, Public hearing 3, 2 December 2019, P-31 [25].
- 20 Transcript, Sarah Forbes, Public hearing 3, 5 December 2019, P-351 [42]–P-352 [12].
- 21 Exhibit 20-3, ‘Statement of Michelle’, 16 November 2021, [90].
- 22 Transcript, Colleen Pearce, Public hearing 3, 3 December 2019, P-137 [26–27].
- 23 *Convention on the Rights of Persons with Disabilities*, opened for signature 30 March 2007, 2515 UNTS 3 (entered into force 3 May 2008), preamble, para (a), (h), (n), (y).
- 24 Transcript, Kate Eastman (Counsel Assisting), Public hearing 30, 21 November 2022, P-11 [40].
- 25 Exhibit 31-003, ‘Statement of Gerard Quinn’, 12 December 2022, at [7].

- 26 *Convention on the Rights of Persons with Disabilities*, opened for signature 30 March 2007, 2515
UNTS 3 (entered into force 3 May 2008), art 12.
- 27 Committee on the Rights of Persons with Disabilities, *General comment no. 1 (2014) Article 12: Equal recognition before the law*, UN CRPD/C/GC/1, (11 April 2014), [13–14].
- 28 Gerard Quinn & Abigail Rekas-Rosalbo, 'Civil death: Rethinking the foundations of legal personhood for persons with a disability', (2016), vol 56, *Irish Jurist*, p 301.
- 29 Ron McCallum, *The United Nations Convention on the Rights of Persons with Disabilities: An assessment of Australia's level of compliance*, Report prepared for the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, October 2020.
- 30 Ron McCallum, *The United Nations Convention on the Rights of Persons with Disabilities: An assessment of Australia's level of compliance*, Report prepared for the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, October 2020, p 53.
- 31 Ron McCallum, *The United Nations Convention on the Rights of Persons with Disabilities: An assessment of Australia's level of compliance*, Report prepared for the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, October 2020, p 53.
- 32 *Convention on the Rights of Persons with Disabilities*, opened for signature 30 March 2007, 2515 UNTS 3 (entered into force 3 May 2008), art 12(4).
- 33 Catalina Devandas Aguilar, *Report of the Special Rapporteur on the rights of persons with disabilities (Theme: Legal capacity reform and supported decision-making)*, UN Doc A/HRC/37/56 (12 December 2017), [30].
- 34 Transcript, Alastair McEwin (Commissioner), Public hearing 1, 16 September 2019, P-16 [13–15].
- 35 Gerard Quinn, 'Putting the human back into human rights – intersectional perspectives', speech, Netherlands Institute for Human Rights Research Annual Conference, June 2021, pp 4–6.
- 36 Ron McCallum, *The United Nations Convention on the Rights of Persons with Disabilities: An assessment of Australia's level of compliance*, Report prepared for the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, October 2020, p 52.
- 37 *Convention on the Rights of Persons with Disabilities: Declarations and reservations (Australia)*, opened for signature 30 March 2007, 2515 UNTS 3 (entered into force 3 May 2008).
- 38 Christine Bigby, Terry Carney, Shih-Ning Then, Ilan Wiesel, Craig Sinclair, Jacinta Douglas & Julia Duffy, Living with Disability Research Centre, *Diversity, dignity, equity and best practice: a framework for supported decision-making*, Report prepared for the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, January 2023, p 1.
- 39 Christine Bigby, Terry Carney, Shih-Ning Then, Ilan Wiesel, Craig Sinclair, Jacinta Douglas & Julia Duffy, Living with Disability Research Centre, *Diversity, dignity, equity and best practice: a framework for supported decision-making*, Report prepared for the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, January 2023, pp 23–24.
- 40 Christine Bigby, Terry Carney, Shih-Ning Then, Ilan Wiesel, Craig Sinclair, Jacinta Douglas & Julia Duffy, Living with Disability Research Centre, *Diversity, dignity, equity and best practice: a framework for supported decision-making*, Report prepared for the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, January 2023, p 1.
- 41 Christine Bigby, Terry Carney, Shih-Ning Then, Ilan Wiesel, Craig Sinclair, Jacinta Douglas & Julia Duffy, Living with Disability Research Centre, *Diversity, dignity, equity and best practice: a framework for supported decision-making*, Report prepared for the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, January 2023, pp 23–24.
- 42 Christine Bigby, Terry Carney, Shih-Ning Then, Ilan Wiesel, Craig Sinclair, Jacinta Douglas & Julia Duffy, Living with Disability Research Centre, *Diversity, dignity, equity and best practice: a framework for supported decision-making*, Report prepared for the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, January 2023, pp 24.
- 43 Christine Bigby, Terry Carney, Shih-Ning Then, Ilan Wiesel, Craig Sinclair, Jacinta Douglas & Julia Duffy, Living with Disability Research Centre, *Diversity, dignity, equity and best practice: a framework for supported decision-making*, Report prepared for the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, January 2023, pp 24–28.
- 44 'Disability, Aging and Carers, Australia: Summary of Findings', *Australian Bureau of Statistics*, web page, 24 October 2019. <www.abs.gov.au/statistics/health/disability/disability-ageing-and-carers-australia-summary-findings/latest-release>
- 45 Australian Bureau of Statistics, *Disability, Ageing and Carers, Australia: Summary of Findings, 2018*, Catalogue number 4430.0, 24 October 2019.

- 46 The population for the question ‘Whether needs assistance to make decisions or think through problems because of disability’ was persons aged 15 or over with a disability.
- 47 Australian Bureau of Statistics, *Disability, Ageing and Carers, 2018*, Results accessed using Australian Bureau of Statistics TableBuilder by age group, by whether has a disability, by whether needs assistance to make decisions or think through problems because of disability.
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- 49 Australian Bureau of Statistics, *Disability, Ageing and Carers, 2018*, Results accessed using Australian Bureau of Statistics TableBuilder by age group, by whether has a disability, by disability groups, by whether needs assistance to make decisions or think through problems because of disability.
- 50 Australian Bureau of Statistics, *Disability, Ageing and Carers, 2018*, Results accessed using Australian Bureau of Statistics TableBuilder by age group, by whether has a disability, by disability groups, by whether needs assistance to make decisions or think through problems because of disability.
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- 53 *Secretary of the Department of Health and Community Services v JWB & SMB (Marion’s Case)* (1992) 175 CLR 218, pp 258–259.
- 54 Terry Ross Carney & David Tait, *The adult guardianship experiment: tribunals & popular justice*, Federation Press, 1997, p 5.
- 55 *Re AAA; Report on a Protected Person’s Attainment of the Age of Majority* [2016] NSWSC 805, [39], [49].
- 56 *Re Application of Local Health District; Patient Fay* [2016] NSWSC 624, [21–23]. See also *Chapman v South Eastern Sydney Local Health District* (2018) 98 NSWLR 208, [22–25]; *Re Leonardo* [2022] NSWSC 1265, [140].
- 57 *Re Application of Local Health District; Patient Fay* [2016] NSWSC 624, [23].
- 58 See for example *Mercy Hospitals Victoria v D1 & Anor* [2018] VSC 519, where a pregnant 17-year-old woman and her mother refused to give consent to a blood transfusion or blood product considered reasonably necessary by her treating medical practitioners to save her life or to prevent serious injury during the course of induction of labour, caesarean section and related procedures, and the postnatal period. The young woman refused to consent because of her desire to adhere to the religious principles of her faith, which she said should be respected as an assertion of her personal autonomy. See also *Re Katey* [2018] FamCA 916.
- 59 *Marion’s Case* (1992) 175 CLR 218.
- 60 *Application of a Local Health District; Re a Patient Fay* [2016] NSWSC 624; *State of Queensland v B* [2008] QSC 231.
- 61 *Mental Health Act 1964* (Tas); Nick O’Neill & Carmelle Peisah, *Capacity and the law*, 3rd edn, Sydney University Press Law Books, 2021, [5.3.1].
- 62 *Guardianship Act 1987* (NSW); *Guardianship and Administration Act 1986* (Vic); *Guardianship and Administration Act 1990* (WA); *Guardianship and Management of Property Act 1991* (ACT); *Public Trustee and Guardian Act 1985* (ACT); *Guardianship and Administration Act 1993* (SA); *Public Trustee Act 1979* (NT). See also: Nick O’Neill & Carmelle Peisah, *Capacity and the law*, 3rd edn, Sydney University Press Law Books, 2021, [5.3.2–5.3.7].
- 63 *Powers of Attorney Act 2014* (Vic); *Guardianship and Administration Act 2019* (Vic); *Medical Treatment Planning and Decisions Act 2016* (Vic); *Mental Health Act 2014* (Vic).
- 64 ‘Guardianship and Administration Act 2019’, *Victoria State Government Justice and Community Safety*, web page. <www.justice.vic.gov.au/justice-system/laws-and-regulation/guardianship-and-administration-act-2019>; Judicial College of Victoria, *Guide to the Guardianship and Administration Act 2019* (Vic), November 2021, pp 8–9.

65 See *Guardianship and Administration Act 2019* (Vic); *Guardianship and Administration Act 2000* (Qld); *Guardianship Act 1987* (NSW); *NSW Trustee and Guardian Act 2009* (NSW); *Guardianship of Adults Act 2016* (NT); *Public Trustee Act 1979* (NT); *Guardianship and Administration Act 1993* (SA); *Guardianship and Administration Act 1995* (Tas); *Guardianship and Management of Property Act 1991* (ACT); *Public Trustee and Guardian Act 1985* (ACT); *Guardianship and Administration Act 1990* (WA).

66 See for example *Guardianship and Administration Act 2000* (Qld) ss 33(1), 35, 36, sch 2; *Guardianship and Administration Act 2019* (Vic) s 38; *Guardianship and Administration Act 1990* (WA) ss 45(2), 46.

67 *Guardianship and Administration Act 2019* (Vic) s 8(1)(c); *Guardianship Act 1987* (NSW) s 4(b); *Guardianship and Administration Act 2000* (Qld) s 11B (Principle 9(b)); *Guardianship and Administration Act 1990* (WA) s 4(4); *Guardianship and Administration Act 1993* (SA) s 5(d); *Guardianship and Administration Act 1995* (Tas) s 6(a); *Guardianship and Management of Property Act 1991* (ACT) ss 4(2)(d), 11; *Guardianship of Adults Act 2016* (NT) s 4(4)(a).

68 *Guardianship and Management of Property Act 1991* (ACT) s 7; *Mental Health Act 2015* (ACT) s 19; *Guardianship and Administration Act 2000* (Qld) s 15; *Guardianship of Adults Act 2016* (NT) s 15; *Guardianship Act 1987* (NSW), ss 3E, 6B; *Guardianship and Administration Act 1993* (SA) s 29; *Guardianship and Administration Act 1995* (Tas) s 21; *Guardianship and Administration Act 2019* (Vic) s 32; *Guardianship and Administration Act 1990* (WA) s 44.

69 In Queensland, New South Wales, the Northern Territory and Tasmania 'Public Guardians'; in South Australia, Victoria and Western Australia 'Public Advocates' (Queensland and the Australian Capital Territory also have a position of 'Public Advocate', but in these jurisdictions this is an independent statutory role that undertakes systems advocacy functions). A public official may also be appointed as a person's financial administrator as a last resort: this official is called the Public Trustee in most states and territories, the 'NSW Trustee and Guardian' in New South Wales and the 'State Trustee' in Victoria. The Australian Capital Territory joins the roles for guardianship and administration under the 'Public Trustee and Guardian'. For a discussion of the different guardianship bodies, see John Chesterman, 'The Future of Adult Guardianship in Federal Australia', (2013), vol 66(1), *Australian Social Work* 26, 27–28.

70 On 1 April 2016, the Guardianship function of the former Public Advocate of the Australian Capital Territory joined the Public Trustee for the territory, forming a new agency: The Public Trustee and Guardian.

71 The Australian Guardianship and Administration Council represents state and territory government agencies that have a role in 'protecting adults in Australia who have a decision-making disability that impairs their capacity to make person or financial decisions.'

72 Australian Guardianship and Administration Council, *Australian Adult Guardianship Orders 2017/18*, Annual report, January 2019.

73 Australian Guardianship and Administration Council, *Australian Adult Guardianship Orders 2017/18*, Annual report, January 2019; Australian Guardianship and Administration Council, *Australian Adult Guardianship Orders 2018/19*, Annual report; Australian Guardianship and Administration Council, *Australian Adult Guardianship Orders 2019/20*, Annual report; Australian Guardianship and Administration Council, *Australian Adult Guardianship Orders 2020/21*, 2022, Annual report.

74 Australian Guardianship and Administration Council, *Australian Adult Guardianship Orders 2020/21*, Annual report, p 1.

75 Australian Guardianship and Administration Council, *Australian Adult Guardianship Orders 2021/22*, Annual report, 2022, p 2.

76 For the Northern Territory, data is only available from 1 December 2017 (all other jurisdiction data starts from 1 July 2017).

77 The data in this table includes data received from Public Advocates, Public Guardians and Public Trustees in October and November 2022.

78 The NSW Civil and Administrative Tribunal was the only tribunal in Australia to report on the age of people subject to applications for guardianship and administration orders for the 2021–22 reporting period: NSW Civil and Administrative Tribunal, *Annual report 2021–22*, p 42 (Graph 5).

79 Exhibit 30-136, 'Statement of Megan Osborne', 14 November 2022, at [33]; Exhibit 30-053, 'Statement of Shayna Smith', 11 November 2022 at [36]; Exhibit 30-081, 'Statement of John Velegrinis', 8 November 2022, at [4.9], Annexure 3; Exhibit 30-008, 'Statement of Pauline Bagdonavicius', 4 November 2022, at [51].

80 Exhibit 30-136, 'Statement of Megan Osborne', 14 November 2022 [32]; Exhibit 30-121, 'Statement of Caroline Cuddihy', 14 November 2022, at [40].

81 Exhibit 30-099, 'Statement of Colleen Pearce', 5 November 2022, at [162].

82 Exhibit 30-099, 'Statement of Colleen Pearce', 5 November 2022, at [161].

83 Exhibit 30-099, 'Statement of Colleen Pearce', 5 November 2022, at [161(a)].

84 Exhibit 30-099, 'Statement of Colleen Pearce', 5 November 2022, at [161(b)].

85 Exhibit 30-099, 'Statement of Colleen Pearce', 5 November 2022, at [161(c)].

86 Exhibit 30-099, 'Statement of Colleen Pearce', 5 November 2022, at [161], [166–167].

87 Exhibit 30-136, 'Statement of Megan Osborne', 14 November 2022, at [148]; Transcript, Megan Osborne, Public hearing 30, 24 November 2022, P-428 [18].

88 Exhibit 30-136, 'Statement of Megan Osborne', 14 November 2022, at [148].

89 Exhibit 30-136, 'Statement of Megan Osborne', 14 November 2022, at [149].

90 Exhibit 30-136, 'Statement of Megan Osborne', 14 November 2022, at [150].

91 Transcript, Shayna Smith, Public hearing 30, 22 November 2022, 206 [1–3].

92 Transcript, Pauline Bagdonavicius, Public hearing 30, 21 November 2022, P-101 [7–21].

93 Exhibit 30-099, 'Statement of Colleen Pearce', 5 November 2022, at [160].

94 Office of the Public Advocate, Submission to the NDIA on the development of an NDIS supported decision making policy, September 2021, pp 9–10.

95 Exhibit 30-191, 'Statement of Scott McNaughton and Sam Bennett', 11 November 2022, at [135].

96 Exhibit 30-191, 'Statement of Scott McNaughton and Sam Bennett', 11 November 2022, at [136].

97 Exhibit 30-191, 'Statement of Scott McNaughton and Sam Bennett', 11 November 2022, at [136].

98 Exhibit 30-099, 'Statement of Colleen Pearce', 5 November 2022, at [163–164]. See also Transcript, Colleen Pearce, Public hearing 30, 24 November 2022, P-344 [5–10].

99 Transcript, Megan Osborne, Public hearing 30, 24 November 2022, P-437 [8–26].

100 Exhibit 30-008, 'Statement of Pauline Bagdonavicius', 4 November 2022, at [176].

101 Transcript, Megan Osborne, Public hearing 30, 24 November 2022, P-428 [30–33], P-429 [4–10]; Exhibit 30-099, 'Statement of Colleen Pearce', 5 November 2022, at [171–73]; Transcript, Colleen Pearce, Public hearing 30, 24 November 2022, P-343 [42–45]; Exhibit 30-053, 'Statement of Shayna Smith', 11 November 2022, at [87–89]; Transcript, Shayna Smith, Public hearing 30, 22 November 2022, P-206 [1–10].

102 Exhibit 30-099, 'Statement of Colleen Pearce', 5 November 2022, at [171–173].

103 Exhibit 30-099, 'Statement of Colleen Pearce', 5 November 2022, at [171].

104 Exhibit 30-099, 'Statement of Colleen Pearce', 5 November 2022, at [173].

105 Exhibit 30-008, 'Statement of Pauline Bagdonavicius', 4 November 2022, at [169].

106 Exhibit 30-008, 'Statement of Pauline Bagdonavicius', 4 November 2022, at [170–171].

107 Exhibit 30-053, 'Statement of Shayna Smith', 11 November 2022, at [89].

108 Exhibit 30-053, 'Statement of Shayna Smith', 11 November 2022, at [89].

109 Exhibit 30-033, TRA.3000.0016.0043, pp 4 [9–41], 5 [20–22]; Exhibit 30-032, IND.0224.0001.0001; Exhibit 30-029, 'Statement of Christine Grace', 17 November 2022, at [46]; Exhibit 30-045, TRA.3000.0016.0011, pp 11 [42], 12 [25], 13 [21–32]; Exhibit 30-062, 'Statement of Uli Cartwright', 27 October 2022, at [12]; Transcript, Uli Cartwright, Public hearing 30, 23 November 2022, P-232 [43] – P233 [24]; Transcript, Austyn, Public hearing 30, 24 November 2022, P-364 [27]–P-365 [8]; Exhibit 30114, 'Statement of Austyn', 8 November 2022, at [16], [18–19]; Exhibit 30-115, NCAT.0001.0041.0001, pp 1–2.

110 Exhibit 30-045, TRA.3000.0016.0011, p 2 [46–47]; Exhibit 30-044, IND.00219.0003.0001.

111 Exhibit 30-045, TRA.3000.0016.0011, p 11 [14–28]; Exhibit 30-044, IND.00219.0003.0001.

112 Exhibit 30-045, TRA.3000.0016.0011, p 11 [30–34]; Exhibit 30-044, IND.00219.0003.0001.

113 Exhibit 30-045, TRA.3000.0016.0011, pp 12 [23]–13 [32]; Exhibit 30-044, IND.00219.0003.0001.

114 Exhibit 30-045, TRA.3000.0016.0011, p 13 [32]; Exhibit 30-044, IND.00219.0003.0001.

115 Exhibit 30-062, 'Statement of Uli Cartwright', 27 October 2022, at [12].

116 Transcript, Alice Barter, Public hearing 30, 21 November 2022, P-56 [33–37]; Transcript, Anthony, Public hearing 30, 21 November 2022, P-21 [31–34]; Transcript, Naomi Anderson, Public hearing 30, 23 November 2022, P-298 [6–8]; Exhibit 30-029, 'Statement of Christine Grace', 17 November 2022, at [21].

117 Exhibit 30-033, TRA.3000.0016.0043, p 4 [33–41]; Exhibit 30-032, IND.0224.0001.0001.

118 Exhibit 30-062, 'Statement of Uli Cartwright', 27 October 2022, at [12].

119 Transcript, Anthony, Public hearing 30, 21 November 2022, P-21 [6–47]; Exhibit 30-001, 'Statement of Anthony', 3 November 2022, at [18]; Exhibit 30-033, TRA.3000.0016.0043, p 8 [5–9]; Exhibit 30-032, IND.0224.0001.0001; Transcript, Uli Cartwright, Public hearing 30, 23 November 2022, P-236 [4–19]; Exhibit 30-062, 'Statement of Uli Cartwright', 27 October 2022, at [20]; Exhibit 30-029, 'Statement of Christine Grace', 17 November 2022, at [33–36].

120 Exhibit 30-033, TRA.3000.0016.0043, p 8 [5–9]; Exhibit 30-032, IND.0224.0001.0001.

121 Transcript, Anthony, Public hearing 30, 21 November 2022, P-21 [6–47]; Exhibit 30-001, 'Statement of Anthony', 3 November 2022, at [18].

122 Exhibit 30-001, 'Statement of Anthony', STAT.0662.0001.0001, at [68].

123 Exhibit 30-062, 'Statement of Uli Cartwright', 27 October 2022, at [16].

124 Transcript, Bakoi Namok, Public hearing 30, 22 November 2022, P-113 [4]–P-114 [35].

125 Exhibit 30-035, TRA.3000.0016.0036, p 5 [32–38]; Transcript, Bakoi Namok, Public hearing 30, 22 November 2022, P-113 [49–50]–P-114 [1]; Exhibit 30-062, 'Statement of Uli Cartwright', 27 October 2022, at [16].

126 'Statement of Uli Cartwright', 27 October 2022, at [16].

127 Transcript, Matilda Alexander, Public hearing 30, 22 November, P-179 [12–14]; Exhibit 30-048, 'Statement of Matilda Alexander', 18 November 2022, at [37].

128 Transcript, Anthony, Public hearing 30, 21 November, P-23 [37–40].

129 Transcript, Anthony, Public hearing 30, 21 November 2022, P-26 [1–2].

130 Transcript, Anthony, Public hearing 30, 21 November, P-26 [1–7].

131 Exhibit 30-007, TRA.3000.0016.0005, p 4; Exhibit 30-006, IND.0216.0002.0001, Exhibit 30-022, 'Statement of Pauline Bagdonavicius', 11 November 2022, at [61], [121–122].

132 Exhibit 30-001, 'Statement of Anthony', 3 November 2022, at [33]; Exhibit 30-022, 'Statement of Pauline Bagdonavicius', 11 November 2022, at [121–122].

133 Transcript, Anthony, Public hearing 30, 21 November 2022, P-30 [18–19].

134 Transcript, Anthony, Public hearing 30, 21 November 2022, P-30 [23–25].

135 Exhibit 30-001, 'Statement of Anthony', 3 November 2022, at [53]; Exhibit 30-003, IND.0213.0001.0005.

136 Transcript, Kate Eastman (Counsel Assisting), Public hearing 30, 21 November 2022, P-11 [1–3].

137 Exhibit 30-114, 'Statement of Austyn', 8 November 2022, at [32]; Transcript, Austyn, Public hearing 30, 24 November 2022, P-373 [1–25].

138 Transcript, Suzanne Nunn, Public hearing 30, 22 November 2022, P-143 [24–29]; Exhibit 30-048, 'Statement of Matilda Alexander', 18 November 2022, at [69–72]; Exhibit 30-077, 'Statement of Naomi Anderson', 16 November 2022, at [18–22].

139 Exhibit 30-001, 'Statement of Anthony', 3 November 2022, at [40]; Transcript, Anthony, Public hearing 30, 21 November 2022, P-29 [40–41].

140 Exhibit 30-001, 'Statement of Anthony', 3 November 2022, at [40–46]; Transcript, Anthony, Public hearing 30, 21 November 2022, P-29 [36] – P-30 [3], [27–30], P-31 [1–5].

141 Exhibit 30-114, 'Statement of Austyn', 8 November 2022, at [30–37]; Transcript, Austyn, Public hearing 30, 24 November 2022, P-371 [13–47]; P-372 [9–11], [17–31]; P-373 [4–6]; P-374 [20–29].

142 Exhibit 30-114, 'Statement of Austyn', 8 November 2022, at [37]; Transcript, Austyn, Public hearing 30, 24 November 2022, P-374 [31]–P-375 [2].

143 Exhibit 30-062, 'Statement of Uli Cartwright', 27 October 2022, at [31–33], [41]; Exhibit 30-073, 'Statement of John O'Donnell', 9 November 2022, at [62].

144 Exhibit 30-073, 'Statement of John O'Donnell', 9 November 2022, at [8]; Transcript, John O'Donnell, Public hearing 30, 23 November 2022, P-261 [20–32].

145 Exhibit 30-073, 'Written statement of John O'Donnell', 9 November 2022, at [25–26]; Transcript, John O'Donnell, Public hearing 30, 23 November 2023, P-269 [40]–P-270 [20].

146 Exhibit 30-073, 'Statement of John O'Donnell', 9 November 2022, at [27–28]; Transcript, John O'Donnell, Public hearing 20, 23 November 2022, P-270 [24–27].

147 Exhibit 30-062, 'Statement of Uli Cartwright', 27 October 2022, at [30–31]; Exhibit 30-073, 'Statement of John O'Donnell', 9 November 2022, at [36].

148 Transcript of Anthony, Public hearing 30, 21 November 2022, P-27 [3–4]; Transcript of Killara, Public hearing 30, 21 November 2022, P-47 [19–20]; Transcript of Suzanne Nunn, Public hearing 30, 22 November 2022, P-138 [21–39].

- 149 Exhibit 30-062, 'Statement of Uli Cartwright', 27 October 2022, at [46].
- 150 Exhibit 30-070, IND.0204.0001.0051, [5].
- 151 Exhibit 30-062, 'Statement of Uli Cartwright', 27 October 2022, at [47]; Transcript, Uli Cartwright, Public hearing 30, 23 November 2022, P-249 [8–12].
- 152 Exhibit 30-062, 'Statement of Uli Cartwright', 27 October 2022, at [47]; Transcript, Uli Cartwright, Public hearing 30, 23 November 2022, P-249 [25–27].
- 153 Exhibit 30-062, 'Statement of Uli Cartwright', 27 October 2022, at [47–48].
- 154 Exhibit 30-062, 'Statement of Uli Cartwright', 27 October 2022, at [49]; Transcript, Uli Cartwright, Public hearing 30, 23 November 2022, P-249 [45]–P-250 [26]; see Exhibit 30-070, IND.0204.0001.0051.
- 155 Exhibit 30-070, IND.0204.0001.0051, p 5.
- 156 Exhibit 30-029, 'Statement of Christine Grace', 17 November 2022, at [23–24], [30–31], [37].
- 157 Exhibit 30-001, 'Statement of Anthony', 3 November 2022, [39–46]; Exhibit 30-114, 'Statement of Austyn', 8 November 2022, at [32]; Transcript, Anthony, Public hearing 30, 21 November 2022, P-35 [20–27].
- 158 Exhibit 30-001, 'Statement of Anthony', 3 November 2022, at [39–46].
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- 163 Transcript, Austyn, Public hearing 30, 24 November 2022, P-370 [30–35].
- 164 Exhibit 30-062, 'Statement of Uli Cartwright', 27 October 2022, at [19–20].
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- 180 Australian Law Reform Commission, *Equality, capacity and disability in Commonwealth laws*, Final report, ALRC report 124, August 2014, recommendation 10-1 and p 99.
- 181 See for example: Senate Community Affairs References Committee, *Inquiry into indefinite detention of people with cognitive and psychiatric impairment in Australia*, November 2016, recommendation 6; Senate Community Affairs References Committee, *Violence, abuse and neglect against people with disability in institutional and residential settings, including the gender and age related dimensions, and the particular situation of Aboriginal and Torres Strait Islander people with disability, and culturally and linguistically diverse people with disability*, November 2015, recommendation 11; Bruce Alston, 'Towards supported decision-making: Article 12 of the convention on the rights of persons with disabilities and guardianship law reform', (2017), vol 35

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1990 (WA) s 113, Sch 1, cl 12; *Public Guardian Act 2014* (Qld) ss 140, 141; *Guardianship and Administration Act 1993* (SA) ss 80, 81; *South Australian Civil and Administrative Tribunal Act 2013* (SA) s 60; *Guardianship and Administration Act 1995* (Tas) s 86; *Tasmanian Civil and Administrative Tribunal Act 2020* (Tas) s 123; *Guardianship of Adults Act 2016* (NT) ss 90, 91; *Northern Territory and Administrative Tribunal Act 2014* (NT) s 62.

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481 *Guardianship and Administration Act 2000* (Qld) s 114A(2).

482 *Guardianship and Administration Act 2000* (Qld) s 114A(8).

483 *Guardianship and Administration Act 2000* (Qld) s 114A(5)–(6).

484 Public Advocate (Queensland), *Public accountability, private lives: Reconsidering the Queensland guardianship system’s confidentiality requirements*, August 2022.

485 Public Advocate (Queensland), *Public Accountability, private lives: Reconsidering the Queensland guardianship system’s confidentiality requirements*, August 2022, p 19.

486 Public Advocate (Queensland), *Public Accountability, private lives: Reconsidering the Queensland guardianship system’s confidentiality requirements*, August 2022, p 20.

487 Public Advocate (Queensland), *Public accountability, private lives: Reconsidering the Queensland guardianship system’s confidentiality requirements*, August 2022, recommendation 3.

488 Public Advocate (Queensland), *Public Accountability, private lives: Reconsidering the Queensland guardianship system’s confidentiality requirements*, August 2022, p 20. (This would be by way of an application for a non-publication order, under section 108 of the *Guardianship and Administration Act 2000* (Qld), which could be made either before, during, or after a guardianship application hearing).

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490 Transcript, Dayne Kingsford, Public hearing 30, 22 November, P-187 [9–22].

491 Transcript, Dayne Kingsford, Public hearing 30, 22 November, P-187 [17–18].

492 Submissions of Counsel Assisting following Public hearing 30, 25 January 2023, p 202 [585].

493 *Guardianship and Administration Act 2019* (Vic) s 15; *Guardianship Act 1987* (NSW) ss 79, 80; *Guardianship and Administration Act 2000* (Qld) ss 209, 209A; *Guardianship and Administration Act 1990* (WA) s 97(1); *Guardianship and Administration Act 1993* (SA) s 21(1); *Guardianship and Administration Act 1995* (Tas) s 15(1); *Public Trustee and Guardian Act 1985* (ACT) s 19B; *Human Rights Commission Act 2005* (ACT) s 27B(1)(a)(iii); *Guardianship of Adults* (NT) s 61(1).

494 Victorian Law Reform Commission, *Guardianship*, Final report 24, April 2012, recommendations 13–18; New South Wales Law Reform Commission, *Review of the Guardianship Act 1987*, Report 145, May 2018, recommendation 13.1(3)(b).

495 *Guardianship and Administration Act 2019* (Vic) ss 15, 16.

496 *Guardianship and Administration Act 2000* (Qld) ss 209, 209A.

497 New South Wales Law Reform Commission, *Review of the Guardianship Act 1987*, Report 145, May 2018, recommendation 13.1.

498 Transcript, Anthony, Public hearing 30, 21 November 2022, P-21 [6–47]; Exhibit 30-032, IND.0224.0001.0001; Transcript, Suzanne Nunn, Public hearing 30, 22 November 2022, P-128 [34–43]; Exhibit 30-042, ‘Statement of Suzanne Nunn’, dated 18 November 2022, at [17]; Transcript, Suzanne Nunn, Public hearing 30, 22 November 2022, P-137 [10–21]; Exhibit 30-042, ‘Statement of Suzanne Nunn’, dated 18 November 2022, at [17]; Exhibit 30-062, ‘Statement of Uli Cartwright’, 27 October 2022, at [20].

499 New South Wales Law Reform Commission, *Review of the Guardianship Act 1987*, Report 145, May 2018, recommendation 13.1(3)(c).

500 New South Wales Law Reform Commission, *Review of the Guardianship Act 1987*, Report 145, 2018, p 207.

- 501 New South Wales Law Reform Commission, *Review of the Guardianship Act 1987*, Report 145, 2018, p 214.
- 502 Office of the Public Advocate (Victoria), *Annual report 2021–2022*, p 43.
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- 504 Exhibit 30-052, ‘Statement of Samay Zhouand’, 10 November 2022, at [183–184].
- 505 Submissions on behalf of the Public Trustee of Queensland following Public hearing 30, [undated], p 4 [4.5].
- 506 Australian Human Rights Commission, *A future without Violence: Quality, Safeguarding and Oversight to Prevent and Address Violence Against People in Institutional Settings*, June 2018, p 40.
- 507 *Guardianship and Administration Act 2019* (Vic) ss 15(c), 16(1); *Public Guardian Act 2014* (Qld) s 12(1)(i); *Guardianship and Administration Act 1990* (WA) s 97(1)(b), (d); *Guardianship and Administration Act 1993* (SA) s 21(1); *Guardianship and Administration Act 1995* (Tas) s 15(1)(a)–(j); *Public Trustee and Guardian Act 1985* (ACT) s 19B(1)(a); *Human Rights Commission Act 2005* (ACT) s 27B(1)(a); *Guardianship of Adults* (NT) s 61(1)(c)–(k).
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- 509 *Guardianship and Administration Act 2019* (Vic) s 15(c).
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- 517 Australian Guardianship and Administrative Council, ‘National Standards for Public Guardianship’ 3rd edn, 2016, p 2; Guardianship and Administrative Council, ‘National Standards for Financial Managers’ August 2018 edn, pp 1–2.
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- 519 Transcript of Anthony, Public hearing 30, 21 November 2022, P-27 [3–4]; Transcript of Killara, Public hearing 30, 21 November 2022, P-47 [19–20]; Transcript of Suzanne Nunn, Public hearing 30, 22 November 2022, P-138 [21–39].
- 520 Transcript, Alice Barter and Christine Grace, Public hearing 30, 21 November 2022, P-60 [5–40].
- 521 Exhibit 30-024, ‘Statement of Alice Barter’, 17 November 2022, at [39], [43].
- 522 Exhibit 30-081, ‘Statement of John Velegrinis’, 8 November 2022, at [14.1–14.2], [16.1]; Exhibit 30-099, ‘Statement of Colleen Pearce’, 5 November 2022, at [123–124]; Exhibit 30-122, ‘Statement of Deborah Simpson’, 14 November 2022, at [37]; Exhibit 30-136, ‘Statement of Megan Osborne’, 14 November 2022, at [80]; Exhibit 30-052, ‘Statement of Samay Zhouand’, 10 November 2022, at [118]; Exhibit 30-053, ‘Statement of Shayna Smith’, 11 November 2022, at [55]; Transcript, Pauline Bagdonavicius, Public hearing 30, 21 November 2022, P-89 [1–8].
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Transcript of Colleen Pearce, Public hearing 30, 24 November 2022, P-351 [43]–P-352 [12].
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- 529 Guardianship and Administrative Council, 'National Standards for Financial Managers'
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- 533 Transcript, 'Austyn', Public hearing 30, 24 November 2022, P-369 [23–26].
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- 539 Exhibit 30-136, 'Statement of Megan Osborne', 14 November 2022, at [73].
- 540 Exhibit 30-053, 'Statement of Shayna Smith', 11 November 2022, at [43–44].
- 541 Exhibit 30-099, 'Statement of Colleen Pearce', 5 November 2022, at [67].
- 542 Exhibit 30-081, 'Statement of John Velegrinis', 8 November 2022, at [10.1–10.4].
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- 549 Shannon Fentiman, *Public Trustee*, Ministerial statement, 15 March 2022.
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- 552 Exhibit 30-073, 'Statement of John O'Donnell', 31 January 2023, at [43].
- 553 Transcript, Uli Cartwright, Public hearing 30, 23 November 2022, P-233 [37–44]; Exhibit 30-045,
TRA.3000.0016.0011, pp 18 [28]–19 [11].
- 554 Exhibit 30-073, 'Statement of John O'Donnell', 9 November 2022, at [60–64]; Transcript,
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'Statement of Uli Cartwright', 27 October 2022, at [32–41]; Exhibit 30-045, TRA.3000.0016.0011,
p 13 [21–32].

555 Exhibit 30-033, TRA.3000.0016.0043, p 4 [33-41], pp 5 [35] – 6 [41], p 11 [22-30], pp 13 [27]-14 [38].
 556 Exhibit 30-001, 'Statement of Anthony', 3 November 2022, at [19], [21] [55]; Transcript, Anthony, Public hearing 30, 21 November 2022, P-24 [14]; Exhibit 30-022, 'Statement of Pauline Bagdonavicius', 11 November 2022, at [54-57]; Exhibit 30-073, 'Statement of John O'Donnell', 9 November 2022, at [48-53]; Transcript, John O'Donnell, Public hearing 30, 23 November 2022, P-274 [33] – P-276 [1].

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560 See for example Name withheld, Submission, 24 November 2021, SUB.100.01664_01, pp 9-10; Name withheld, Submission, 2 February 2022 [SUB.001.01540_01, pp 1-2]; Name withheld, Submission, 29 December 2022, SUB.001.03335_01, p 7.

561 Transcript, Uli Cartwright, Public hearing 30, 23 November 2022, P-234 [25-28], P-236 [21-27]; Exhibit 30-062, 'Statement of Uli Cartwright', 27 October 2022, at [12], [28b], [29b], [43-45].

562 Transcript, Uli Cartwright, Public hearing 30, 23 November 2022, P-234 [25-28], P-236 [21-27]; Exhibit 30-062, 'Statement of Uli Cartwright', 27 October 2022, at [12], [29b], [43-45].

563 Exhibit 30-062, 'Statement of Uli Cartwright', 27 October 2022, at [45].

564 Exhibit 30-062, 'Statement of Uli Cartwright', 27 October 2022, at [28(c)]; Exhibit 30-066, IND.0204.0001.0025, p 2.

565 Exhibit 30-062, 'Statement of Uli Cartwright', 27 October 2022, at [29a, b].

566 Transcript, Uli Cartwright, Public hearing 30, 23 November 2022, P-246 [8-16].

567 Exhibit 30-062, 'Statement of Uli Cartwright', 27 October 2022, at [37]; Transcript, Uli Cartwright, Public hearing 30, 23 November 2022, P-246 [18-24].

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569 Exhibit 30-052, 'Statement of Samay Zhouand', 31 January 2023, at [66], [194-205].

570 Exhibit 30-052, 'Statement of Samay Zhouand', 31 January 2023, at [200]; The Queensland Public Trustee, Steps to Financial Independence Pathway Guidelines, pp 1-2.

571 Exhibit 30-052, 'Statement of Samay Zhouand', 31 January 2023, at [201-202].

572 Exhibit 30-052, 'Statement of Samay Zhouand', 31 January 2023, at [203].

573 Exhibit 30-052, 'Statement of Samay Zhouand', 31 January 2023, at [199].

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575 Exhibit 30-081, 'Statement of John Velegrinis', 8 November 2022, at [24.1-24.4], [25.2-25.4].

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577 Exhibit 30-122, 'Statement of Deborah Simpson', 31 January 2023, at [22].

578 Exhibit 30-122, 'Statement of Deborah Simpson', 31 January 2023, at [53].

579 *NSW Trustee and Guardian Act 2009* (NSW) s 71.

580 Exhibit 30-122, 'Statement of Deborah Simpson', 31 January 2023, at [54-55].

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582 Transcript, Josie Brown, Public hearing 30, 23 November 2022, P-329 [7-24].

583 Transcript, Josie Brown, Public hearing 30, 23 November 2022, P-329.

584 Exhibit 30-052, 'Statement of Samay Zhouand', 10 November 2022, at [195].
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585 Exhibit 30-073, 'Statement of John O'Donnell', 9 November 2022, at [65].

586 Exhibit 30-096, 'Statement of Josephine Brown', 21 November 2022, at [5(6)-(7)].

587 Exhibit 30-096, 'Statement of Josephine Brown', 21 November 2022, at [6].

588 Victorian Ombudsman, *Investigation into State Trustees*, June 2019, p 57 [218].

589 Victorian Ombudsman, *Investigation into State Trustees*, June 2019, p 57 [221].

590 Victorian Ombudsman, *Investigation into State Trustees*, June 2019, p 57 [221].

591 Victorian Ombudsman, *Investigation into State Trustees*, June 2019, pp 57 [222], 76 [308].

592 Victorian Ombudsman, *Investigation into State Trustees*, June 2019, p 7 [13].

593 Victorian Ombudsman, *Investigation into State Trustees*, June 2019, p 57 [221], [223].

594 Victorian Ombudsman, *Investigation into State Trustees*, June 2019, p 97 [Recommendation 10].
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 597 Victorian Ombudsman, *Investigation into State Trustees*, June 2019, recommendation 3.
 598 Exhibit 30-081, 'Statement of John Velegrinis, State Trustee of Victoria, 8 November 2022,
 [25.1(4)].
 599 Queensland Public Trustee, *Steps to Financial Independence – Empowering customers to
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 600 Victoria Legal Aid, *State of trust – making sure State Trustees protects and promotes the rights
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 STL.0001.0002.0004, p 1; PricewaterhouseCoopers, for the Queensland Government, *Review
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 p 50; Public Trustee for the Northern Territory, *Annual report 2021–2022*, p 10.
 603 Queensland Public Advocate, *Preserving the financial futures of vulnerable Queenslanders:
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Investigation into State Trustees, June 2019; Damian Bugg, Independent Review of the Public
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 604 Queensland Public Advocate, *Preserving the financial futures of vulnerable Queenslanders:
 A review of Public Trustee fees, charges and practices*, January 2021, p 39 [180–182].
 605 Victorian Ombudsman, *Investigation into State Trustees*, June 2019, p 65 [259].
 606 Queensland Public Advocate, *Preserving the financial futures of Vulnerable Queenslanders:
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 the Auditor General of Western Australia, *Public Trustee's Administration of Trusts and Deceased
 Estates* (2022), pp 11–12.
 607 Queensland Public Advocate, *Preserving the financial futures of vulnerable Queenslanders:
 A review of Public Trustee fees, charges and practices*, January 2021 [183–187].
 608 Queensland Public Advocate, *Preserving the financial futures of vulnerable Queenslanders:
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 609 Office of the Auditor General of Western Australia, *Public Trustee's Administration of Trusts and
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 611 Victorian Ombudsman, *Investigation into State Trustees*, June 2019, p 90 [370].
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- 628 Victorian Ombudsman, *Investigation into State Trustees*, June 2019, p 65 [256].
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- 632 Damian Bugg, Independent Review of the Public Trustee Tasmania, 30 November 2021, p 50.
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- 635 Queensland Public Advocate, *Implementation Update: Preserving the financial futures of vulnerable Queenslanders: A review of Public Trustee fees, charges and practices*, 10 March 2022, p 2.
- 636 PricewaterhouseCoopers, for the Queensland Government, *Review of fees and charges Public Trustee of Queensland*, 24 June 2022, p 9.
- 637 PricewaterhouseCoopers, for the Queensland Government, *Review of fees and charges Public Trustee of Queensland*, 24 June 2022, pp 11–31.
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- 647 Submissions of Counsel Assisting following Public hearing 30, p 200 [579].
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- 651 Australian Institute of Health and Welfare, Response to questions from the Royal Commission, 4 October 2022, CTD.9999.0094.0001, p 1.

- 652 *Australian Institute of Health and Welfare Act 1987* (Cth) s 5; Christine Bigby, Terry Carney, Shih-Ning Then, Iain Wiesel, Craig Sinclair, Jacinta Douglas & Julia Duffy, Living with Disability Research Centre, *Diversity, dignity, equity and best practice: A framework for supported decision-making*, Report prepared for the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, January 2023, recommendation 4.8, p 7.
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3. Advocacy and informal supports

Key points

- Advocacy plays a key role in enabling people with disability to realise their rights, exercise autonomy and access services and supports.
- People with disability use self-advocacy to make positive changes on an individual and systemic level. Parents and carers also play an important advocacy role, particularly in health and education settings.
- Independent advocates are also essential in many situations, including when a specific skill set is needed, in closed or segregated settings, or where a person lacks informal supports.
- Funding for national advocacy programs is not meeting demand. Additional funding is needed to ensure people with disability can access advocacy support.
- There is a lack of data on the demand for advocacy services at both the national and state and territory levels. Data collection should be improved so that it can inform ongoing additional funding for advocacy.
- There are some specialist First Nations and culturally and linguistically diverse advocacy services, but service coverage is not nationwide and does not adequately meet population needs. As a result, First Nations and culturally and linguistically diverse people with disability have to access generalist disability advocacy as best they can. Generalist disability advocacy providers need more training to ensure culturally safe service delivery.

3.1. Introduction

The Royal Commission's terms of reference direct us to consider the critical role advocates play in providing care and support to people with disability.¹ This chapter explores that issue and also examines the importance of informal supports for people with disability.

Disability advocacy means acting, speaking or writing to promote, protect and defend the human rights of people with disability. There are several forms of disability advocacy:²

- Self-advocacy is where someone with disability speaks up and represents themselves, sometimes with support and training from community-based groups.
- Individual advocacy is a one-on-one approach, undertaken by a professional advocate, relative, friend or volunteer.
- Systemic advocacy involves working for long-term social change to ensure that the collective rights and interests of people with disability are met through legislation, policies and practices.

There is a direct relationship between self-advocacy, individual advocacy and systemic advocacy. Systemic advocacy identifies common issues at the individual level and addresses the root causes. When successful it reduces or removes the need for self-advocacy and individual advocacy because it leads to better laws, policies and service systems.

All forms of disability advocacy seek to safeguard and raise awareness of the rights of people with disability. Ms Margherita Coppolino is a woman of short stature and an advocate and disability and inclusion consultant. At Public hearing 31, 'Vision for an inclusive Australia' she told us:

Advocacy seeks to ensure that all people in society are able to have their voices heard on issues that are important to them. Protect and promote their rights. Have their views and wishes generally considered when decisions are being made about their lives, and to speak for themselves ... Advocacy makes our lives safer and helps us to equally enjoy our human rights.³

At Public hearing 30, 'Guardianship, substituted and supported decision-making', Dr Colleen Pearce, Victorian Public Advocate, recognised the role of advocacy in both protecting people with disability from abuse, and uncovering abuse when it occurs:

Having an independent person involved makes it more likely that violence, abuse, neglect or exploitation will be discovered. Advocacy support to build the person's informal support networks, community connections and self-advocacy capability can also prevent abuse from occurring in the first place.⁴

This chapter begins by examining the role of advocacy in the lives of people with disability. It examines the barriers to accessing advocacy support, and sets out our proposed solutions and recommendations. In particular, we examine:

- whether current funding for advocacy services is adequately meeting demand
- the need for improved data collection and reporting
- the importance of culturally safe advocacy.

This chapter also examines 'informal supports' for people with disability – that is, their relationships and connections with peer groups, support networks and the broader community. Informal supports are a critical part of advocacy. They can build the capacity of a person with disability to self-advocate, but informal supporters can also advocate on behalf of a person with disability.

Advocacy is essential for many people with disability to understand and exercise their rights. In Volume 4, *Realising the human rights of people with disability*, we recommend that an Australian Disability Rights Act be enacted and include the right of people with disability to access and use supports in making and participating in decisions that affect them, communicating their will and preferences, and developing their decision-making ability. This includes the right to access and use advocacy services. The recommendations in this chapter complement our proposals in Volume 4.

3.2. The role and value of advocacy

Recognition of advocacy's critical role

Legislation and a national framework

The *National Disability Insurance Scheme Act 2013* (Cth) (*NDIS Act*) general principles recognise 'the role of advocacy in representing the interests of people with disability'.⁵ The *NDIS Act* states that this role 'is to be acknowledged and respected'. It recognises that advocacy supports people with disability by:⁶

- promoting their independence and social and economic participation
- promoting choice and control in the pursuit of their goals and the planning and delivery of their supports
- maximising independent lifestyles of people with disability and their full inclusion in the mainstream community.

The *Disability Services Act 1986* (Cth) defines an 'advocacy service' as:

a service that seeks to support persons with disabilities to exercise their rights and freedom, being rights and freedoms recognised or declared by the Disabilities Convention, through one-to-one support; or supporting them to advocate for themselves, whether individually, through a third party or on a group basis.⁷

The National Disability Advocacy Framework (NDAF) also recognises the critical role of advocacy. The NDAF was established in 2012. An updated 2023–2025 NDAF, developed in consultation with people with disability, was released in June 2023.⁸

As part of the 2023–2025 NDAF the Australian Government and all state and territory governments have committed to the following objective:

People with disability have access to effective disability advocacy that promotes, protects and ensures their full and equal enjoyment of all human rights, enabling full community participation and inclusion.⁹

A Disability Advocacy Work Plan (the Work Plan) has been developed to support the implementation of the 2023–2025 NDAF. The Work Plan outlines:

priority areas of work for the Australian Government, state and territory governments to collaboratively support the outcomes listed in the [2023 –2025 NDAF]. Jurisdictions have discretion to determine which Work Plan actions they wish to participate in, and implementation of the Work Plan actions may be undertaken within jurisdictions' existing budgets, resources, and priorities.¹⁰

Previous reports and inquiries

Past reports and inquiries have found that advocacy services play an important role in ensuring a person with disability can identify and report mistreatment. This is particularly the case in situations where a person may be afraid to complain, has complex communication needs or faces additional barriers to reporting violence, abuse and neglect as a result of their disability.¹¹

The NSW Ombudsman reported that advocates are particularly important for people with disability without an informal support network, or where the person and their informal supports need assistance to raise concerns.¹²

The New South Wales Ageing and Disability Commissioner recognised that in addition to a reactive role, managing crises and complaints, advocacy should have a proactive role in preventing and safeguarding.¹³ The Commissioner described the importance of advocacy in:

- safeguarding people from abuse and neglect
- protecting and promoting the human, legal and civil rights and safety of people with disability
- supporting people with disability to determine their own will and preferences
- enabling people with disability to access appropriate supports and services that maximise independence, autonomy, productivity and inclusion
- informing and achieving systemic responses to the needs and aspirations of people with disability
- supporting people with disability to take an active part in public debate and government decision-making that affects them.¹⁴

Self-advocacy

As noted above, self-advocacy means people with disability speaking out and representing themselves.¹⁵ Some people with disability often require assistance from informal support networks or advocacy organisations to build the skills and self-confidence required to self-advocate effectively. For example, advocacy organisations can provide human rights education and awareness.¹⁶

Positive impact of self-advocacy

In many hearings, the Royal Commission heard about the importance of self-advocacy, across a range of settings, in preventing violence, abuse, neglect and exploitation. Witnesses explained how building skills in self advocacy increased their confidence, allowed them to overcome their 'fear of being hurt and not being treated as equal', and made them realise that they could make a difference in their own lives and the lives of others.¹⁷

At Public Hearing 4, 'Health care and services for people with cognitive disability', some witnesses explained how important it is for people with cognitive disability to be their own advocates and develop skills to do this. Two witnesses who described themselves as self-advocates spoke about what it means to advocate for their own health care. They told the Royal Commission that they have developed the skills and knowledge not only to make their own voices heard, but also to teach other people how to speak up for themselves.¹⁸ Ms Kylie Scott said:

For me, being an advocate means that I can spread my wings and put people with disability under my wing. I can get people with disability to realise what speaking out means.¹⁹

At Public hearing 28, 'Violence against and abuse of people with disability in public places', Carly Findlay described herself as an 'appearance activist'.²⁰ Her evidence demonstrated that her public self-advocacy not only benefits herself but also gives other people with disability confidence in themselves and inspires them to become advocates:

I know my work online and offline helps other people become more confident in their own skin, to advocate for disability rights, and to develop disability pride. As an example, a friend of mine who has Ichthyosis told me that she had hidden her skin for over 40 years because of the shame she attached to it. After she found me and heard about my experience, she felt the courage to be open about her Ichthyosis and her other diagnoses. She is no longer afraid to wear sleeveless dresses and has told me that she has begun to feel human again. My friend is now an incredible advocate and ally for the disability community. Examples such as this are the reason why I continue to show up and advocate publicly. This is why, despite the abuse and hate that I have received, I refuse to be silenced.²¹

At Public hearing 29, 'The experience of violence against, abuse, neglect and exploitation of people with disability from culturally and linguistically diverse communities', we heard from witnesses who had achieved positive changes through self-advocacy. For example, we heard evidence from Ms Natalie Sandon-Stanhope, a Deaf woman who advocated for her own access to appropriately skilled interpreters in university.²² This advocacy was successful and the university provided interpreters, which was necessary for her to complete her degree.²³ Ms Sandon-Stanhope also gave evidence of advocating for access to interpreters in other settings, including a yoga training course. Because of her advocacy, two interpreters were assigned to the class and another Deaf person was able to join the class.²⁴

At the same public hearing, Ms Anaab Rooble, a community leader, told us that embracing her disability and asking for access to her university's carpark and lift was essential to being able to complete her degrees.²⁵ We also heard from Ms Esther Simbi, an advocate and author, who started to advocate for herself from a young age.²⁶ Ms Simbi said she was often late to university classes as her disability made it difficult to walk long distances between lectures and tutorials, so she asked university's disability services for assistance. This resulted in her being able to access a wheelchair when needed, and the university also introduced a system where other people could book to use the wheelchair.²⁷ Ms Simbi's self-advocacy also resulted in her getting an NDIS plan review and the support she needed:

I had difficulty securing NDIS funding to meet all of my individual needs and goals for the first three years after joining the NDIS. However, in August last year, I had a major surgery on my elbow (which was my second surgery in five months). This prompted the NDIS to release more funding to support me as I was physically out of action for months and I needed help with in-home support and community access.

Because of my high English language proficiency and confidence to vocalise and articulate my needs, I was able to request a plan review and get the support I needed. However, there are many people with disability from culturally and linguistically diverse backgrounds who do not know that they could request ... a plan review.²⁸

Evidence also demonstrated the critical role self-advocacy organisations play in training and supporting people with disability to self-advocate and pursue systemic change.²⁹ At Public hearing 31, we heard how self-advocacy organisations support people to know their rights. They also build capacity and provide training for people with disability so they can self-advocate.³⁰ In the words of Ms Coppolino, 'the best self-advocacy training is provided by other advocates'.³¹

At Public hearing 17, 'The experience of women and girls with disability with a particular focus on family, domestic and sexual violence', Ms Kobie Hicks explained how WWILD Sexual Violence Prevention Association Inc (WWILD), which supports people with intellectual disability who have experienced sexual abuse or crime, taught her to self-advocate and speak out about abuse. She said, 'they taught me to have a voice about ... what's happened to me, and that [is] how I become strong'.³²

At Public hearing 30, Mr John O'Donnell shared his experience of being involved in Rainbow Rights, a self-advocacy group for people with intellectual disability identifying as LGBTIQ+.³³ Mr O'Donnell said it is important to him to have a community in Rainbow Rights, which understands him both as a person with disability and a person identifying as LGBTIQ+.³⁴ Mr O'Donnell has also worked with All Abilities Advocacy for approximately two years.³⁵ He recounted a number of benefits from engaging with advocacy organisations:

I have gained advocacy skills through my involvement with Rainbow Rights and Advocacy group and All Abilities. The skills that I have learnt have helped me to understand what kinds of supports I need around me to help me make my own decisions.³⁶

At Public hearing 28 we heard from Ms Julie Butler, Advocacy Practice Leader for Speak Out Tasmania, an advocacy service and member organisation for people with intellectual disability.³⁷ Speak Out Tasmania facilitates peer support and self-advocacy groups. As an example, some members of Speak Out Tasmania were experiencing abuse at the Glenorchy bus mall. They wrote to the Glenorchy Council to raise their concerns.³⁸ The council met with Tasmania Police and the public transport provider and this resulted in increased security cameras and improved safety.³⁹

Talulla*

Talulla, mid-40s, has intellectual disability.

In her 20s, she wanted to be more independent and find a place of her own.

'I like living with other people. I feel safer. Being alone would not do me any good.'

Talulla's mum helped her find a community group home.

'But it didn't work out,' Talulla told the Royal Commission. She didn't have much in common with the other residents and everyone had different support needs.

After some time, Talulla had had enough.

'So I stood up to my mum and said, "I want to move on."'

Talulla moved to a purpose-built home with three older residents. They have become good friends and do a lot of things together.

'The carers are good. And they take us away sometimes, and it's good fun.'

Once a week, Talulla attends a self-advocacy course to help her 'stick up for [her] rights' at home and at work.

She has become a disability ambassador and advocates for herself and the other residents.

'That means I make sure that the carers are doing the right thing. I'm making sure they don't abuse us or hurt us or anything like that.'

One of the things Talulla has learnt is to calmly tell support workers they need to knock before they enter her or the other residents' rooms.

She makes sure 'that people are listened to'.

Talulla also advocates in her workplace.

‘If you don’t get paid, I’ll be talking to them.’

Talulla is concerned advocacy isn’t very well funded in her state.

‘We need money for our self-advocacy course.’

Currently, Talulla is involved in advocating for more timely access to mobility aids and for public transport to be more accessible.

‘Some people always wait for a very long time to get a wheelchair ... We need help to get that organised. We don’t want them falling over.’

She is also advocating for people to be able to leave the homes they are in if there are problems.

‘They tell me that some of the staff are a little bit rude and arrogant. And then I’ll say to them, “Well that’s not fair.” I mean, people should respect the client, instead of being rude to them.’

Talulla is happy. Being able to advocate makes her feel safer.

‘We need that voice.’

* This is a de-identified narrative of an experience shared with us in a submission or private session. The person who shared their experience was not a witness. They did not give evidence, take an oath or give an affirmation. Nothing in this narrative represents a finding of the Royal Commission and any views expressed are those of the person, not of the Royal Commission.

Limits on self-advocacy

It is important to recognise that some people with disability face unique barriers and may have limited capability to self-advocate. Their personal circumstances or high support needs may mean they will require independent advocacy support.

People with disability living in group homes are often discouraged from self-advocating. Ms Sarah Forbes, advocacy manager at Victorian Advocacy League for Individuals with Disability (VALiD), gave evidence at Public hearing 3, 'The experience of living in a group home for people with disability'. She said residents of group homes are often unaware of their human rights and, even if they are informed, often 'have experiences of attempting to exercise their rights and not being respected or ... being retaliated against for doing that'.⁴⁰ Mr Kevin Stone, then CEO of VALiD, gave similar evidence:

Lots and lots of people with disability, particularly people living in closed settings, group homes, institutions across this country, they don't know that they're safe. They don't know that there are people around to look out for them. They, many times in many situations, live in fear. If they speak up, they will be hurt. The repercussions of them speaking up will be taken out on them either physically, psychologically, or in the opportunities that are denied to them. We see it constantly.⁴¹

In other cases, even skilled self-advocates will require assistance from family members or independent advocates. At Public hearing 4, Ms Scott said even with her self-advocacy and independent living skills, she needs some help from her mother in navigating the health system, particularly organising appointments and making decisions about her health.⁴²

At Public hearing 31, Ms Coppolino said she has used and benefited from almost all forms of advocacy, including self-advocacy.⁴³ Through self-advocacy, she 'learned skills about how to speak up for [herself] and defend [her] rights'.⁴⁴ She also highlighted the need for independent advocacy services, even for those with a high level of skill in self-advocacy:

Sometimes I've been ignored and been too beaten down to self-advocate, so I've got professional advocates to support me and sit beside me and advocate with and for me.⁴⁵

The importance of independent advocacy is discussed further later in this section.

Family advocacy

Families and carers are often the most immediate source of support for people with disability. They play a critical role in advocating for people with disability and in preventing violence, abuse, neglect and exploitation.

Health settings

At Public hearing 4, witnesses told the Royal Commission that strong advocacy is crucial to ensure people with cognitive disability get quality health care. Parents often play a central role. Professor Stephen Leeder spoke about the importance of supporting parents to be advocates because ‘there’s nothing like the advocacy of an individual who understands the patient’.⁴⁶

At Public hearing 4, 16 parents gave evidence about their experiences as advocates for their children with cognitive disability. In some cases, parents advocate for their children by helping them communicate with health professionals so that they can speak up for themselves and make their own decisions. Mr Robert Strike AM said he encourages his daughter to speak for herself and talk directly to doctors, but he is ‘always behind her or next to her’. He said it is important that people have their parent or advocate with them when talking to doctors ‘to make certain they are being listened to’.⁴⁷

Some parents described their advocacy as ‘fighting’ for their child’s right to quality care and treatment. Ms Toni Mitchell said from the moment her son Joshy was born, she ‘had to start justifying my son’s right to live and to be treated’.⁴⁸ A number of parents recounted their experiences of advocating for the most basic, and in some cases life-sustaining, treatment for their children.⁴⁹

Parents can be strong and effective advocates for their children and in some cases become ‘de facto health professionals’.⁵⁰ Because of their extensive knowledge of their children’s needs and preferences, and deficiencies in continuity and co-ordination of care within the health system, parents can also assume responsibility for the case management of their child’s health.⁵¹

Ms Lyn Porter, who works as an official community visitor in New South Wales, said people with cognitive disability who do not have a parent or support person capable of managing their health ‘are falling through the cracks because nobody’s connecting the dots’.⁵²

Advocating for their child’s health takes a toll on many parents. At least three witnesses described this penalty as ‘normal’ family life for them. In some cases, it is their own physical and mental health. At least two parents said they feared passing away because there would be no-one to take on the role of advocating for their child.⁵³

Education settings

In the context of education, parents and other family members of students with disability often undertake advocacy.⁵⁴

In Public hearing 29, Ms Sandon-Stanhope told us that, when she enrolled in high school, her parents successfully advocated for her to attend a mainstream school. The school was an oral early education school and she was the first Deaf signing student to enrol there.⁵⁵ Ms Sandon-Stanhope also advocates for her own children, who are Deaf. She had successfully advocated to her local council to provide a signing role model at child care.⁵⁶ Dr Breda Carty told us that

her mother was very supportive during her education and this had helped her to achieve at school. She said her mother was a strong advocate and ensured teachers understood her needs.⁵⁷

However, as with experiences in the health system, it can be a 'battle' for families to advocate for their child to be included in schools and other education institutions.⁵⁸ Advocating for a child with disability in school requires a significant amount of time and knowledge of educational systems, and can be a stressful and 'exhausting'.⁵⁹ Families may lack the financial and emotional resources to pursue complaints, and may have limited access to advocates for support.⁶⁰

In Public hearing 24, 'The experience of children and young people with disability in different education settings', Ms Brittney Wilson gave evidence about her experiences in advocating for herself and her younger brother James, who lives with disability, when at school.⁶¹ She described being James' 'protector' at school and said that James would often go to her and they would resolve issues together.⁶²

Disability service provision

Family members may raise concerns about matters that go unnoticed by disability support workers or may have become normalised. For example, in Public hearing 14, 'Preventing and responding to violence, abuse, neglect and exploitation in disability services (a case study)', we heard how Ms Karen Rogers had complained to the South Australian Department of Human Services about the physical environment of her son Daniel's home and about his grooming and personal hygiene.⁶³

In Public hearing 20, 'Preventing and responding to violence, abuse, neglect and exploitation in disability services (two case studies)', we heard how 'Sophie's parents, 'Greg' and 'Michelle', had raised concerns with Life Without Barriers about her personal hygiene.⁶⁴ The parents of 'Robert' and 'Rebecca' raised concerns about their supported accommodation provided by Life Without Barriers. The concerns included failures to carry out basic repairs or clean the house.⁶⁵ Rebecca's mother, 'Catherine', repeatedly complained about the level of interpersonal violence and conflict in the same house.⁶⁶

Independent advocates support families

At Public hearing 4, Dr AAJ said that, despite being a doctor herself, on one occasion she felt unable to advocate adequately for her son on her own.⁶⁷ One private session participant described how, even as a nurse, she struggles to advocate for the proper health treatment for her brother who has disability:

I think of families who don't have my background as a nurse or who ... can't just speak up and advocate. I just think what's happening to other people with disability when I can't even get that to happen for my brother.⁶⁸

Several witnesses highlighted the difficulties for people with cognitive disability who are unable to advocate strongly for themselves and who have no family capable of doing so.⁶⁹ Ms Christine Regan and Dr Rebecca Kelly shared their experiences of navigating the health system for their children. They said it had been a challenge, but they recognised they had a level of privilege in their capacity to do so. They are aware many people with cognitive disability do not have the benefit of strong advocacy support from their parents.⁷⁰ Dr Kelly said rhetorically:

What on earth happens to the child whose parents do not have the education, who are intellectually disabled themselves, who place their full trust in medical practitioners, or for whom English is not a first or even second language?⁷¹

Similar issues arose in the context of education. The Royal Commission heard that families need support in understanding their child's rights and need access to advocacy support to navigate the education system.⁷² Where families may not have the knowledge or ability to advocate for their children, independent advocates can be invaluable in safeguarding the inclusion of children with disability in education.⁷³ Independent advocates can also be useful when the relationship between an educational institution and a family is deteriorating or has broken down.⁷⁴

Ms Michelle O'Flynn and Ms Nikki Parker from Queensland Advocacy for Inclusion explained:

In many schools the quality of the inclusion is often proportional to the advocacy, energy and efforts of the families of students, which means that even within the same school the 'inclusion' experienced by students is highly variable.⁷⁵

A parent advocate raised similar concerns in a private session. They worried that a 'two-tiered system' is developing for children with disability: those with parents who 'have the time and the resources' to advocate for their children and those who do not.⁷⁶ AAC, a teacher and parent of children with disability, also raised this concern. She noted many parents of children with disability lacked the means or knowledge to effectively advocate for their children in school.⁷⁷

In Public hearing 7, 'Barriers experienced by students with disability in accessing and obtaining a safe, quality and inclusive school education and consequent life course impacts', Ms Catriona (Kate) de Bruin said systemic barriers are especially difficult for families whose first language is a language other than English.⁷⁸

Independent advocacy

Independent advocacy is an essential complement to self-advocacy and family advocacy. It may be required in a range of circumstances – for example, when a specific skill set is needed, in closed settings, or where a person with disability lacks informal supports.

The Department of Social Services defines an independent advocate as someone who:⁷⁹

- is independent of the organisations that provide supports or services to a person with disability
- provides independent advocacy for the person with disability, assists the person with disability to exercise choice and control and to have their voice heard in matters that affect them
- acts at the direction of the person with disability, and follows the person with disability's expressed wishes, will, preferences and rights
- is free of relevant conflicts of interest.

This definition is consistent with the definition of an independent advocate in the *NDIS Act*.⁸⁰ The only difference is that the first point in the Department of Social Services definition covers a broader range of supports and services, whereas the *NDIS Act* definition specifies independence from NDIS-related organisations.

This chapter adopts the Department of Social Services definition, as it covers a broader range of settings.

Ensuring people with disability feel heard

Witnesses told us that having an independent advocate involved changed the dynamics of their interactions and made them feel listened to. Mr Geoffrey Thomas, a First Nations person with disability, gave evidence at Public hearing 11, 'The experiences of people with cognitive disability in the criminal justice system'. He said independent advocacy:

Gives a voice, because I can say what I want to say, the courts aren't happy, the hospital doesn't want me. But when [my advocate] says, 'Listen, we've referred him, we've been involved in,' they go, 'Now it's believable'.⁸¹

Evidence in Public hearing 28 demonstrated that when people with disability tell police about an incident of violence or abuse, believing they are making an official report that will be followed up, police will often consider it an informal 'chat' about a 'low-level incident' that does not merit a response.⁸² Ms Butler of Speak Out Tasmania said when advocates contacted police on behalf of a person with disability, the police often responded much more proactively.⁸³ For instance, after being contacted by advocates, police would offer 'to meet the person [who experienced the incident] in their home and discuss the issue and try to ... make recompense for the fact ... they hadn't responded' in the first place.⁸⁴

We heard similar evidence at Public hearing 7. Ms O'Flynn explained, when dealing with education systems, 'the moment an advocate is engaged, there is a significant change in response from the school and from the department [of education] with better outcomes for students'.⁸⁵

At Public hearing 32, 'Service providers revisited', evidence indicated, for people with disability who have no or limited family support, advocates may be the only way to raise concerns and complaints. Northcott said it had obtained an advocate to support a complainant who was allegedly sexually assaulted. It had done so because the complainant was subject to a guardianship order and had no other support networks besides staff.⁸⁶ However, Northcott used disability advocates infrequently, 'as they are hard to engage due to having very limited availability'.⁸⁷

Advocacy Tasmania's response to the *Rights and attitudes issues paper* noted that, when people with disability have experienced being 'talked over or ignored' by NDIS workers, 'as soon as they [NDIS worker] know someone's watching [a professional advocate] it's different'.⁸⁸

Improving outcomes

Independent advocacy results in better outcomes for people with disability. At Public hearing 26, 'Homelessness, including experience in boarding houses, hostels and other arrangements', 'Charlotte' gave evidence about how her advocate helped her. She said she can now ensure people listen to her before they make decisions about her life.⁸⁹ Charlotte told us she had experiences of violence, abuse and exploitation while living in a boarding house. Because of this, she did not want to live in shared accommodation, except as a last resort. Her advocate had helped her prepare a will, obtain an enduring power of attorney and obtain a guardianship order that reflects this in writing. Charlotte said as a result, she no longer needs to worry about being put into a group or nursing home.⁹⁰

At Public hearing 29, Ms Simbi gave evidence about how an independent advocacy service helped her to secure accessible public housing.⁹¹ It also assisted her in resolving workplace discrimination issues and applying for a disability parking permit.⁹²

At Public hearing 20, 'Preventing and responding to violence, abuse, neglect and exploitation in disability services (two case studies)', we heard that raising issues with or about the NDIS can be difficult for people who are not familiar with its systems.⁹³ This was also emphasised in private sessions and submissions. Advocacy in dealing with the NDIS is particularly crucial where disability service providers abuse their position by exploiting or otherwise maltreating their clients. For example, one advocate discovered that a support service was taking more money from their client's package than they were supposed to. The advocate was able to draw attention to and end this exploitation.⁹⁴ In a number of submissions and private sessions, we were also told of instances in which advocates helped to identify and address misuse of NDIS funds.⁹⁵

AMPARO Advocacy's submission shared the example of a woman with disability from a culturally and linguistically diverse background who AMPARO contacted through its 'Targeted Outreach Project'. They had connected her to an advocate, who supported her to get her 'very poor' NDIS plan reviewed and improved.⁹⁶ The advocate had also assisted her to receive income support from Centrelink and to gain independence from her abusive partner.⁹⁷ Another submission described the experience of 'KW', a woman who experienced prolonged physical

and psychological abuse in her group home. When advocates eventually reached her, KW was ‘incredibly fearful of everyone’, ‘extremely depressed and wanted to die’.⁹⁸ Her income was tied to the group home and care service, and they ‘controlled all aspects of her life’. The advocates eventually managed to have her funding separated and worked to have her guardianship awarded to her mother.⁹⁹ With access to advocacy, KW was able to leave her abusive group home and live an independent life with her mother.¹⁰⁰

‘Jennifer’, who gave evidence at Public hearing 20, is the mother of ‘Natalie’, a woman with cognitive disability. She told us Natalie was indecently assaulted in her group home by a male support worker. Jennifer said the sexual assault counsellors ‘went above and beyond in their support of Natalie’ and ‘really helped’ them.¹⁰¹ She said:

they really advocated for Natalie in relation to increasing her financial independence, and helped Anna and I understand how financial management orders and the NSW Trustee and Guardian worked and how application to the NSW Civil and Administrative Tribunal could be submitted.¹⁰²

At Public hearing 11, the Royal Commission heard that advocates have an essential role in safeguarding people with cognitive disability in the criminal justice system, and supporting them to participate in justice. Ms Taylor Budin, who is autistic, spoke of the value of having access to one person through the Cognitive Impairment Diversion Program (CIDP) to advocate for her and explain what was going on while she was in prison.¹⁰³ Ms Budin said if she had had access to supports like the CIDP when she first went to court, it ‘would have been a whole different story’.¹⁰⁴ She told us that, without this support, she would still be in prison.¹⁰⁵

Absence of independent advocacy

At Public hearing 4, Dr AAJ said there is a ‘hidden community’ of people who do not have access to specialist care. She spoke about decisions to send patients to palliative care that she felt were made prematurely because they did not have an advocate to challenge that decision and push for specialist treatment.¹⁰⁶

Ms Julie Bury gave evidence at Public hearing 30. Ms Bury lived with Parkinson’s disease and was subject to a financial administration order. The Queensland Public Trustee was her appointed administrator. Ms Bury did not have an advocate throughout the legal process of having the orders removed. However, she told us an advocate during that time would have helped her because:

they could have explained what it was all about. I would know what a functional capacity test was, I would know what I had to do, and I could have been independent in working it out. I was dependent on another person. I was dependent on [redacted] and the GP to explain it to me, to work out what I needed and walk me through it.¹⁰⁷

Ann, a young First Nations mother with paranoid schizophrenia, gave evidence at Public hearing 8, ‘The experiences of First Nations people with disability and their families in contact with child protection systems’.¹⁰⁸ She described being admitted to hospital while experiencing

a psychotic episode. At the hospital she signed papers without the benefit of legal advice or the support of a non-legal advocate.¹⁰⁹ The papers were about the removal of her son from her care on a short-term order.¹¹⁰ She later reflected that, if she had legal representation at this time, a lawyer could have advised her about the consequences of her decision.¹¹¹ She had not understood that the order meant her son might remain in a foster placement for the next five years.¹¹²

Challenges in closed settings, including group homes

Advocacy is a key factor in promoting the safety of people with disability in group homes. However, people with disability face unique barriers to accessing disability advocacy if they live in supported accommodation.¹¹³ We have already discussed the challenges of exercising self-advocacy in a group home environment. People with disability who are receiving disability services face similar barriers in accessing independent advocacy and building informal support networks.

Group homes can be isolating and can prevent residents from participating in their local communities.¹¹⁴ Opportunities for building informal support networks can be limited or non-existent. We heard this can be because 'staff perceived their purpose for being there as being to look after people' instead of 'to build relationships and participate in the community'.¹¹⁵

We also heard that staff and management of group homes are in the position to exert control over their residents' lives, creating an environment in which violence and abuse is more likely to occur.¹¹⁶ The lack of visibility and inclusion means that residents and people outside of the group home can find it very difficult to identify and address violence, abuse, neglect and exploitation.¹¹⁷

At Public hearing 3, Mr Stone said 'the only strategy he had ever seen that is capable of making a difference [in group homes] is advocacy'.¹¹⁸ He detailed a number of cases of abuse and neglect in group homes where his organisation has advocated. These included residents being assaulted by staff,¹¹⁹ reports of violence being dismissed or not believed¹²⁰ and staff refusing to provide clean and sanitary living conditions for residents.¹²¹ Mr Stone said knowledge about this mistreatment only came to light through the work of advocates.¹²²

Other witnesses gave similar evidence. They said advocates represent a connection between their clients and their broader communities. Advocates can provide an outside perspective that can identify and work to prevent or address violence, abuse, neglect or exploitation.¹²³ At Public hearing 13, 'Preventing and responding to violence, abuse, neglect and exploitation in disability services (a case study)', 'Eliza' described the difference it made to her sister, 'Melissa', when she had assistance from a skilled advocate.¹²⁴

However, many people in group homes do not have access to independent advocates. At Public hearing 3 we heard it can be difficult for group home residents to contact advocacy services,¹²⁵ and that staff in group homes can limit the information clients can access about advocacy.¹²⁶ At Public hearing 29 we heard people working as part of d/Deafblind peer groups were prevented from accessing residents once an issue was raised with the house manager.¹²⁷

At Public hearing 32, Ms Frederikke Jensen of VALiD told us about advocacy work in closed settings such as group homes, in both crisis situations and for day to day decisions.¹²⁸ Ms Jensen said ‘there are people whose voices are simply not heard unless you actually mandate ... that they should have that kind of advocacy and support for decision-making.’¹²⁹

This is consistent with information that the Disability Advocacy Network Australia (DANA) shared with us. Members described ‘difficulty accessing people in supported accommodation settings’,¹³⁰ being ‘refused access to the local supported co-living homes in my area’,¹³¹ and ‘a culture of closedness within some of those group homes’.¹³²

NDIS participants and people with disability in supported accommodation need increased access to independent advocates. This especially applies for those who have high support needs and/or no or few informal supports. Advocates can help ensure that people with disability do not fall into gaps between mainstream and disability services.¹³³ They can also be the difference between a person being able to make or participate in decisions about their lives and a person having decision-making taken away from them.¹³⁴

National Disability Services, Australia’s peak industry body for non-government disability service organisations, told us it strongly supports appropriately funded reforms to increase advocacy and self-advocacy development for people with disability. It considers that greater investment is needed in advocacy programs and independent advocacy services both within and outside the NDIS.¹³⁵

We discuss the role of disability advocacy for NDIS participants further in Volume 10, *Disability services*. We also discuss the difference between the role of advocates and support coordinators.

Barriers to accessing advocacy have also been identified in other closed settings, including prisons. Mr George Newhouse, Director and CEO of the National Justice Project, gave evidence at Public hearing 27, ‘Conditions in detention in the criminal justice system’. He stressed the importance of independent organisations having flexible access to prisons that detain people with disability, to provide ‘transparency and openness’ and advocate about what they witness first hand.¹³⁶ Ms Deborah Kilroy, CEO of Sisters Inside, also emphasised the importance of independent advocates in ensuring accountability and transparency in closed justice (for example, detention) settings.¹³⁷

Systemic advocacy

Disability representative organisations and disability advocacy organisations undertake systemic advocacy with the aim of achieving wide-scale change. These organisations undertake systemic advocacy through a variety of means. This includes:

- preparing alternative or ‘shadow’ reports for the Committee on the Rights of Persons with Disabilities in respect of Australia’s compliance with the *Convention on the Rights of Persons with Disabilities (CRPD)*¹³⁸
- members of disability representation and advocacy organisations sitting on various advisory bodies, for example Australia’s Disability Strategy Advisory Council, discussed briefly in Volume 5, *Governing for Inclusion*

-
- preparing submissions and giving evidence to a range of reviews and inquiries, including this Royal Commission
 - appearing in the media to advocate for the human rights of people with disability.

The establishment of this Royal Commission marked the culmination of years of systemic advocacy by disability advocates and people with disability, as we discussed in Volume 2, *About the Royal Commission*.

Ms Coppolino highlighted, at Public hearing 31, systemic advocacy was an important factor in the development of the NDIS:

I'm a participant of NDIS and NDIS would never have been created had it not been for systemic advocacy that people with disabilities and Disabled People's Organisations fought for.¹³⁹

Systemic advocacy has also improved the lives and realised the rights of people with disability living in group homes. At Public Hearing 3, Professor Patsie Frawley of Deakin University gave the example of an amendment to the *Family Violence Protection Act 2008* (Vic). Advocacy groups for women with disability lobbied the government to have the Act reformed to include group homes as a 'family-like environment' so that certain forms of abuse in group homes could be treated as acts of family violence.¹⁴⁰ This had a significant benefit for group home residents who are seeking justice for violence they have experienced. The reform also influenced the way group home staff viewed their role in residents' lives, reflecting that group homes are the residents' homes. The homes are a 'family-like environment' in which they live.¹⁴¹

Systemic advocacy has played a particularly crucial role in informing people with disability during the COVID-19 pandemic and in preventing violence, abuse, neglect and exploitation. At Public hearing 5, 'Experiences of people with disability during the ongoing COVID-19 pandemic', the Royal Commission heard how disabled people's organisations and advocacy groups increased systemic advocacy in the health sector throughout the pandemic.¹⁴² These groups:

- engaged in providing information in accessible formats
- undertook surveys and collected data about the impact of COVID-19
- identified gaps in the governments' responses and action
- advocated for services
- lobbied governments and business
- participated in the Advisory Committee
- attended roundtables
- prepared reports and information
- engaged with the media
- supported people with disability and their families.

3.3. Advocacy funding

The Australian Government and state and territory governments provide funding to disability advocacy organisations through specific programs, discussed in this section.

The NDIS funds some forms of decision-making support and capacity building through Individual Funded Packages for NDIS participants and through activities funded by the Information, Linkages and Capacity Building program. However, individual advocacy services are not available as NDIS-funded supports.¹⁴³

The Productivity Commission found in its 2011 report *Disability care and support* that the NDIS should not fund advocates. The report referred to ‘the conflict of interest that would arise were the NDIS to fund advocacy bodies whose role was to challenge the disability system overseen by the NDIS’.¹⁴⁴

National advocacy programs

The National Disability Advocacy Program (NDAP) and the NDIS Appeals Program are the two main national disability advocacy programs.

Table 6.3.1 shows the funding for these programs from 2012–13 onwards.¹⁴⁵

Table 6.3.1: Funding for the National Disability Advocacy Program and NDIS Appeals Program, 2012–13 to 2022–23

Year	NDAP (\$m)	NDIS Appeals Program (\$m)	Total (\$m)
2012–13	\$16.1 m	Nil	\$16.1 m
2013–14	\$16.6 m	\$0.6 m	\$17.3 m
2014–15	\$16.5 m	\$0.9 m	\$17.4 m
2015–16	\$16.2 m	\$1.0 m	\$17.2 m
2016–17	\$17.6 m	\$5.6 m	\$23.2 m
2017–18	\$18.1 m	\$9.5 m	\$27.6 m
2018–19	\$20.5 m	\$11.1 m	\$31.5 m
2019–20	\$21.7 m	\$11.3 m	\$32.9 m
2020–21	\$21.7 m	\$14.9 m	\$36.6 m
2021–22	\$24.8 m	\$15.4 m	\$40.2 m
2022–23	\$24.3 m (est.)	\$7.1 m (est.)	\$35.5 m (est.)

Sources: Funding for 2012–13 to 2018–19 is from information received under notice from the Australian Government.¹⁴⁶ Funding for 2019–20 to 2021–22 is from the Department of Social

Services Annual report 2021-22.¹⁴⁷ Funding for 2022–23 is estimated based on 2022–23 Budget commitments over three years (\$73 million for NDAP¹⁴⁸ and \$21.2 million for the NDIS Appeals Program,¹⁴⁹ equally allocated across the three-year funding period).

National Disability Advocacy Program

The NDAP funds disability advocacy providers to provide advocacy support across Australia.¹⁵⁰ The Australian Government describes it as providing ‘people with disability with access to effective disability advocacy that promotes, protects and ensures their full and equal enjoyment of all human rights enabling community participation’.¹⁵¹

Organisations receive funding under the program to deliver:¹⁵²

- advocacy for individuals, which may involve individual advocacy, self-advocacy, citizen advocacy, family advocacy and/or legal advocacy
- systemic advocacy.

Funding agreements for most providers require 90 per cent of resources to be used to support individual advocacy, and 10 per cent to support systemic advocacy activities.¹⁵³

The target group, defined under section 8 of the *Disability Services Act 1986* (Cth), consists of people who have a disability that:¹⁵⁴

- is attributable to an intellectual, psychiatric, sensory or physical impairment or a combination of such impairments
- is permanent or likely to be permanent
- results in a substantially reduced capacity of the person for communication, learning or mobility, and the need for ongoing support services.

There are two categories of advocacy providers:¹⁵⁵

- ‘generalist’ providers support people with any type of disability or cultural background
- ‘specialist’ providers support people with disability who:
 - have a specific type of disability
 - have specific issues such as with housing, education or employment
 - are from culturally and linguistically diverse backgrounds
 - are First Nations.

In 2021–22 there were three culturally and linguistically diverse specific organisations, and two First Nations specific organisations funded under the NDAP.¹⁵⁶ This is out of a total of 59 providers as at April 2022.¹⁵⁷

Based on information available in October 2020 regarding issues that individual advocates addressed under the NDAP:

- 51 per cent of advocacy support was reported to relate specifically to the NDIS.¹⁵⁸ NDIS Access/Planning (15 per cent) and NDIS internal review (12 per cent) were the most common issues, accounting for a total of 27 per cent of all issues raised.¹⁵⁹
- Housing and legal matters were the most frequently raised non-NDIS issues, accounting for almost 20 per cent of all issues raised.¹⁶⁰

Nakoa*

Nakoa was born overseas and has limited family support in Australia.

A few years ago, when he was in his late 50s, he had a stroke. He is unable to walk and uses a wheelchair. He needs help with personal care, to complete daily tasks and to access the community.

'I depend on support workers to ensure that I lead a quality life.'

Nakoa told the Royal Commission that after the stroke, thanks to the NDIS, he was able to remain in his own home.

However, he found the NDIS confusing. He wasn't sure what service providers, support coordinators or plan managers actually did.

'All I know was that I was receiving services as I had an approved NDIS Plan.'

But at some stage, Nakoa's NDIS funds ran out.

His support coordinator at the time didn't tell Nakoa this had happened. With no discussion he moved Nakoa to a nursing home, telling him it was a week of respite. Nakoa ended up being there for three months.

During this time Nakoa engaged an advocate. The advocate discovered Nakoa's funds had been depleted weeks before he went to the nursing home. When the support coordinator realised the problem, he handed Nakoa off to the local area coordinator. The local area coordinator decided to send Nakoa to a nursing home.

The advocate discovered that Nakoa's plan only funded 3.5 hours of support each day. This was not adequate – Nakoa was receiving 8.5 hours each day.

I had no idea what happened to my funds and why no-one put in an application to the NDIA for change of my circumstances to access more funding. It was surely foreseeable that the funds were running out, but no-one put in a review, as a result hence I was left without any supports.

Nakoa's advocate organised a new NDIS plan and service provider, and helped him leave aged care. Nakoa had to pay thousands of dollars for the three-month stay in aged care, leaving him in financial distress.

'I was left with about \$70 in my account. I eventually went home. I had no money for medication or food. I had to rely on my friend to help me financially. I was distressed and anxious at this point.'

Nakoa complained to the NDIS Quality and Safeguards Commission and is waiting for the outcome.

'All the events ... have caused me stress, upset and I couldn't sleep which are not good for my mental health.'

Nakoa is keen to recover the money he lost staying in aged care, but there is no guarantee he will get it back.

* This is a de-identified narrative of an experience shared with us in a submission or private session. The person who shared their experience was not a witness. They did not give evidence, take an oath or give an affirmation. Nothing in this narrative represents a finding of the Royal Commission and any views expressed are those of the person, not of the Royal Commission.

NDIS Appeals Program

In addition to the NDAP, the Australian Government funds the NDIS Appeals Program. The Appeals Program is for people with disability, and other people affected by reviewable decisions of the National Disability Insurance Agency (NDIA).¹⁶¹ It provides support to people seeking review of these decisions in the Administrative Appeals Tribunal or other dispute resolution models.¹⁶²

There are two types of support available under the NDIS Appeals Program:¹⁶³

- access to a skilled disability advocate who acts as a support person – this service is provided by the same organisations funded under the NDAP (discussed above)
- access to funding for legal services, where there is wider community benefit and/or an applicant is experiencing disadvantage and would substantially benefit from legal representation – this service is provided by legal aid commissions, and applicants must meet eligibility criteria set by legal aid commissions.

As at April 2022, the NDIS Appeals program funded 42 NDAP providers and eight legal aid commissions.¹⁶⁴

Independent Expert Review program

The Australian Government is also trialling the Independent Expert Review program in 2022–23. The program aims to reduce the number of cases that need to be heard by the Administrative Appeals Tribunal. It provides funding for advocacy and legal support for NDIS participants who are invited to have their case considered through the program.¹⁶⁵ In 2022–23, \$12.4 million was allocated by the Australian Government to trial the Independent Expert Review program. This included \$6.6 million in additional advocacy and legal support for NDIS participants.¹⁶⁶

Under the trial, a disability expert independent of the NDIA reviews individual cases and makes a recommendation to the NDIA. The NDIA has also adopted an early resolution approach to reduce the likelihood of the matter going through the Administrative Appeals Tribunal.¹⁶⁷

We note that data released in March 2023 indicated a reduction in the number of cases before the tribunal.¹⁶⁸

Other funding

The Australian Government has committed funding to disability advocacy over the last four years in addition to the NDAP and the NDIS Appeals Program.

To support the implementation of Australia's Disability Strategy 2021–2031 (ADS) at the national level, the Australian Government committed \$9.9 million to 'improve individual advocacy services for people with disability, supporting advocates to improve their individual advocacy service offering, and increasing access to advocacy through piloting a telephone and internet

service'.¹⁶⁹ This included \$1.7 million per year from 2022–23 to 2024–25 and \$0.7 million per year from 2025–26 to 2031–32 to implement the Disability Advocacy Support Helpline pilot and the National Centre for Disability Advocacy.¹⁷⁰

In addition, the Australian Government:

doubled existing support for systemic disability advocacy in the 2022–23 October budget. This increased annual funding from \$2.6 million per year to over \$5.2 million per year.¹⁷¹

Finally, the Australian Government funded free and independent advocacy, counselling and legal support services for people engaging with or affected by the work of the Royal Commission. For details, see Volume 2, *About the Royal Commission*.

This included funding for the Disability Royal Commission Individual Advocacy Support program, administered by the Department of Social Services. The program aimed to support people with disability and their carers who were engaging with, or affected by, the Royal Commission. Approximately \$102 million was allocated over the period 2019–20 to 2021–22 for counselling and advocacy support services.¹⁷²

Some of the funding was distributed to existing NDAP providers to provide additional advocacy services. Funding was also provided to support advocacy through the First Peoples Disability Network, and systemic advocacy via peak disability representative organisations.¹⁷³

Following the extension of the Royal Commission to September 2023, the Australian Government allocated an additional \$48.4 million to the Department of Social Services in 2022–2023 and 2023–2024 for advocacy, support and counselling services.¹⁷⁴

This amounts to a total of \$150.4 million or an average of \$37.6 million per annum allocated to advocacy, support and counselling services through the Department of Social Services. This annual investment exceeds the amount of funding we recommend the Australian Government commit to disability advocacy in Recommendation 6.21.

We recount how advocacy services played a critical role in helping people with disability engage with us in Volume 2, *About the Royal Commission*.

State and territory funding for advocacy

Many of the issues that require advocacy support for people with disability relate to service systems that state and territory governments are responsible for, including housing, transport, education, child protection and health. At Public hearing 4, Dr AAJ told the Royal Commission, in her experience, 'a patient with an intellectual disability needs a strong advocate within the health system; without one they may suffer, or at worst they may die'.¹⁷⁵ At Public hearing 7, Ms Sayers, former CEO of Children and Young People with Disability, told us the funding and capability of the advocacy sector needs to be urgently built to assist in realising 'inclusive' education in Australia.¹⁷⁶ She said state-based funding for disability advocacy services tends to be short-term and insecure.¹⁷⁷

The Productivity Commission's Report on NDIS Costs (2017) supported all governments funding advocacy services:

If advocacy is funded solely by the Australian Government, then there may be pressure to help participants access services that are funded by the states and territories. But if advocacy is funded solely by the States and Territories, there may be pressure to help participants to enter the NDIS and use services funded by the Australian Government. The previous practice – where the Australian, State and Territory Governments all contributed to disability advocacy funding – is appropriate to address this concern. It also reflects the fact that advocates help people with disability to prevent and resolve issues in all government services, and the interface between these services.¹⁷⁸

This aligns with information the Department of Social Services provided to the Royal Commission:

States and territories are responsible for ensuring the service systems they administer are accessible to people with disability within their jurisdiction, and in this context, the Australian Government considers they should continue to fund individual advocacy in relation to enabling effective access to those services.¹⁷⁹

We agree states and territories play a critical role in funding advocacy services. However, the certainty and amount of advocacy funding that states and territories provide has fluctuated over the past decade. The Productivity Commission's review of the National Disability Agreement (2019) noted:

Some States have withdrawn and then reinstated funding for the period covering the transition and earlier stages of the NDIS. It appears that some governments may be operating on a 'wait and see' basis pending confirmation of what funding will be provided through the Australian Government's National Advocacy Program and the NDIS.¹⁸⁰

In the same year, the New South Wales Ageing and Disability Commissioner's Review into Disability Advocacy in New South Wales stated that 'the disability landscape, including for disability advocacy services, has changed dramatically with the introduction of the National Disability Insurance Scheme'.¹⁸¹ The review also acknowledged that 'the responsibility for and the level of funding of advocacy and related services has been uncertain',¹⁸² and that 'the NSW Government's direct funding contribution to advocacy reduced after alternative funds under the NDIS came into the sector'.¹⁸³ Importantly, the review stated:

Although patterns of disability advocacy activity have changed, a constant body of work remains in relation to advocating directly with many NSW Government departments, such as Health, Housing, Education, Transport and Justice.¹⁸⁴

Following the Review, the NSW Government introduced the Disability Advocacy Futures Program (see Table 6.3.2).

In 2020, the South Australian Government established the Safeguarding Task Force to ‘examine the current gaps in oversight and safeguarding for people living with disability in South Australia’.¹⁸⁵ The task force found the South Australian Government ‘has not invested in individual advocacy to assist people with disabilities to navigate the service system and the community’.¹⁸⁶ It recommended the South Australian Government ‘invest in individual advocacy to assist individuals with accessing what they need from the NDIS and from the community’.¹⁸⁷ In response, the government committed funding for a new individual advocacy service. This was the first time disability advocacy had been funded in South Australia since 2007.¹⁸⁸

Table 6.3.2 outlines state and territory advocacy programs. We note, for many of these programs, there is limited publicly available information on the funding allocated and the number of clients they serve. This has constrained our ability to compare funding across jurisdictions and to assess whether funding in each jurisdiction broadly reflects population needs.

Table 6.3.2 State and territory disability advocacy programs

State/territory	Advocacy programs
New South Wales	The Disability Advocacy Futures Program funds individual, systemic and representative (membership organisations run by or on behalf of people with disability) advocacy providers to ensure that all people with disability in New South Wales have access to New South Wales Government funded and delivered services.¹⁸⁹ The program commenced on 1 January 2022. It implements the recommendations of the Ageing and Disability Commissioner’s 2019 review of disability advocacy funding in New South Wales.¹⁹⁰ New South Wales has allocated \$112.5 million over four years to disability inclusion, including to facilitate the Disability Advocacy Futures Program.¹⁹¹ The Justice Advocacy Service supports adults and young people with a cognitive impairment who are in contact with the New South Wales criminal justice system – as victims, witnesses and suspects/defendants. The service is available across the state. It uses an individual advocacy approach by providing a support person for the person with disability.¹⁹²
Victoria	The Victorian Disability Advocacy Program (VDAP) funds a range of non-government organisations to deliver advocacy services to people with disability.¹⁹³ These services offer a variety of individual advocacy, self-advocacy and systemic advocacy support, and are generally open to people with disability (whether or not they have an NDIS plan), their carers and families.¹⁹⁴

State/territory	Advocacy programs
Victoria	Agencies funded under the VDAP received a 25 per cent increase in core funding in 2018–19 and 2019–20. This was again increased to 40 per cent for six months in 2020 to support agencies to respond to the increase in demand due to the COVID-19 health emergency.¹⁹⁵ Additionally, 'in 2021–22, the Victorian Government allocated a further \$1.7 million in VDAP services to increase service access. In 2022–23 the Victorian Government invested a further \$1.8 million in VDAP services to increase service access.'¹⁹⁶ The Disability Advocacy Resource Unit resources the disability advocacy sector in Victoria, but does not provide a direct advocacy service.¹⁹⁷ The Self Advocacy Resource Unit resources and supports Victorian self-advocacy groups of people with intellectual disability, acquired brain injury and complex communication support needs.¹⁹⁸
Australian Capital Territory	The Australian Capital Territory Government has committed to providing ongoing funding for individual and systemic advocacy services to promote the rights of people with disability and foster inclusive communities.¹⁹⁹
Queensland	The Queensland Disability Advocacy Program provides grants to organisations to deliver individual advocacy services to Queenslanders with disability, their families and carers.²⁰⁰ The Queensland Government allocated \$5.9 million in funding for the Queensland Disability Advocacy Program from 1 January 2022 to 30 June 2023. The funding was divided into three service types: Queensland Disability Advocacy Hub, Specialist Individual Advocacy, and Regional Individual Advocacy.²⁰¹ The Queensland Disability Advocacy Hub provides a leadership role on state-wide systemic advocacy issues. It also provides centralised phone support and referrals for all people with disability.²⁰² Three specialist individual advocacy services are funded to provide advocacy to priority cohorts: First Nations people with disability, culturally and linguistically diverse people with disability, and children and young people with disability (and their carers and/or guardians).²⁰³ Regional individual advocacy services provide advocacy support for all people with disability across all cohorts and disability types. Organisations are selected by region. They must be able to demonstrate capacity to provide individual advocacy across the entire region.²⁰⁴ The Queensland Disability Peak and Representative Bodies Program 2022–2025 provides funding to nine services to deliver state-wide accessible and disability-specific information and referral services to people with disability and their families and carers and to promote community awareness. These organisations also provide expert advice and feedback to government on a range of matters impacting people with disability and unpaid carers.²⁰⁵ This program was allocated \$4.2 million over three years.²⁰⁶

State/territory	Advocacy programs
Northern Territory	Individual advocacy services are available for people with disability. The Disability Advocacy Service provides support to people with disability in Central Australia (Alice Springs, Amoonguna and Tennant Creek). ²⁰⁷ The Darwin Community Legal Service provides general advocacy support for people with disability in the Top End. ²⁰⁸
Western Australia	The Funded Advocacy Program supports individual advocacy services for people with disability, as well as their families and carers. ²⁰⁹ Systemic advocacy organisations also receive funding support. ²¹⁰ The State's 2022–23 budget committed \$15 million over three years for individual and systemic advocacy. ²¹¹
South Australia	A state wide disability advocacy service , run by Uniting Communities, is provided to 'ensure vulnerable South Australians with disability can access and receive the supports they require under the NDIS and in the community'. ²¹² The service assists NDIS participants (and their carers) with legal advocacy and self-advocacy. ²¹³ The South Australian Government committed \$1.2 million to the program over 2020–2023. This is the first time disability advocacy has been funded in the state since 2007. ²¹⁴
Tasmania	Individual advocacy services are available in Tasmania. At the time of writing this <i>Final report</i> , Tasmania had funding agreements in place until June 2023 across three independent advocacy organisations – Speakout Advocacy, Advocacy Tas (Your Say) and the Association for Children with Disability (ACD). All three provide individual advocacy support. ²¹⁵

In addition to these programs, Victoria, Queensland and the Australian Capital Territory have independent Offices of the Public Advocate who are responsible for systemic disability advocacy.²¹⁶

The need for states and territories to improve their data collection to ensure sufficient, ongoing and stable funding for their advocacy programs is discussed in section 3.4 and addressed in Recommendation 6.22.

We also encourage states and territories to review and improve the information they have publicly available about their advocacy programs and how to access them. This is particularly important in health, housing, education and justice settings. We further discuss the importance of advocacy in these settings in Chapter 4, 'Health care and treatment' in this volume and in Volume 7, *Inclusive education, employment and housing*. There is also a role for states and territories to take steps to better connect people with disability to advocacy services in these settings. In Volume 7, we recommend that state and territory governments create or expand complaints management offices that operate within education entities to help resolve complaints about schools. These offices should be empowered to connect families with advocacy support.

Funding is not meeting demand

In its 2019 Concluding Observations on Australia, the Committee on the Rights of Persons with Disabilities expressed concern regarding funding for advocacy. It noted '[t]he unsustainability and inadequacy of resources for continuous, individual and independent advocacy programmes'.²¹⁷

The Committee recommended Australia:

Ensure that persons with disabilities are able to access continuous, sustainable and adequately resourced individual and independent advocacy programmes, particularly those not part of the National Disability Insurance Scheme.²¹⁸

In January 2019, the Productivity Commission's Review of the National Disability Agreement found there was a lack of clarity on the Australian Government's and state and territory governments' responsibilities for the provision of disability advocacy services. It found an analysis identifying community needs and government objectives and assessing them against planned or available services would help to identify service gaps.²¹⁹

In December 2019, the former Council of Australian Governments (COAG) Disability Reform Council acknowledged the importance of disability advocacy and agreed to undertake work to better understand the drivers of demand for independent disability advocacy and decision-making support.²²⁰ In July 2020, ministers noted progress on the analysis, and reports of increasing demand for advocacy services. They stated 'findings of this analysis will inform decisions on future arrangements for the funding of independent disability advocacy and decision-making supports'.²²¹

At the time of writing, the analysis commissioned by the former COAG Disability Reform Council had not been completed. However, information obtained from the Department of Social Services under notice indicates funding is not sufficient to meet demand.

This information is contained in a draft report titled 'Disability Advocacy and Decisions Supports: Demand and Gap Analysis, Report' dated October 2020 (Draft Demand and Gap Report) prepared by ASK Insight for the Department of Social Services, and states and territories. We understand the states and territories have not endorsed the Draft Demand and Gap Report for publication.

In preparing the Draft Demand and Gap Report, ASK Insight conducted a survey of 48 disability advocacy organisations, with assistance from Disability Advocacy Network Australia.²²² Through this survey, advocacy services reported their ability to meet eligible requests had been declining over the period 2016–17 to 2018–19. By 2018–19, one in four eligible people did not receive assistance.²²³

Key issues identified by surveyed advocacy providers (two-thirds of whom were funded under the NDAP)²²⁴ include:

-
- All organisations reported an increase in demand for advocacy services in the three years to May 2020, with 70 per cent indicating there had been a major increase in demand (more than 20 per cent growth).²²⁵
 - Almost all respondents (87 per cent) indicated uncertainty about future funding had impacted their organisation. In particular, this had led to an inability to plan and to recruit and retain skilled staff.²²⁶
 - In terms of service gaps, the top three concerns were funding (adequacy and predictability), insufficient geographic coverage of advocacy services to provide access to all Australians with disability, and insufficient training and professional development for advocates.²²⁷

In addition to an increase in the number of people seeking advocacy support, NDAP data indicated:

in the two years to October 2020 there had been increased complexity in the matters brought to advocacy providers, and that cases were taking longer/requiring more resources to resolve.²²⁸

We understand that states and territories indicated to the Disability Reform Minister's Meeting that they considered the data captured in the Draft Demand and Gap Report to be inaccurate and an unreliable basis for conclusions on the disability advocacy landscapes. It is not clear whether states' and territories' concerns related to the ASK Insight survey.

Unmet demand for advocacy services

In many public hearings, the Royal Commission heard the lack of adequate or consistent funding is a major factor contributing to the unmet demand for disability advocacy.²²⁹

At Public hearing 3, Ms Forbes said her organisation, VALiD, was 'wildly under-resourced' for the work it was expected to do. She said, as a result of underfunding, many advocacy organisations have had to limit their work and their client intake, leaving some people unable to find advocacy services that can support them.²³⁰

Since April 2020, Queensland Advocacy for Inclusion's Education Advocacy Service has assisted more than 30 families of students in state schools. The service has been unable to support approximately 20 other families because of 'capacity constraints' or because the students were in schools other than state schools.²³¹ Ms Sayers from Children and Young People with Disability Australia also explained that specific children and youth-focused disability advocacy services have been oversubscribed for years.²³²

Ms Jen Blyth is the CEO of Deaf Australia, the peak advocacy body for all d/Deaf, Deafblind and hard of hearing people in Australia who use Auslan.²³³ Ms Blyth gave evidence at Public hearing 29. She said that Deaf Australia is a systemic advocacy organisation but often provides individual advocacy 'because there [are] no individual advocacy organisations around Australia that are resourced'. She noted it does so despite being a small organisation that is under-resourced.²³⁴

At Public hearing 32, a panel of advocates stressed the funding challenges for advocates and advocacy organisations.²³⁵ They gave evidence that there is a shortage of independent advocates and advocacy services across Australia, which means that not all people with disability who require independent advocacy are able to access it.²³⁶ Ms Leigh of National Disability Services recognised this. She said the lack of consistent funding for advocacy services was a ‘risk to the system’.²³⁷

Submissions to the Royal Commission support the evidence raised at hearings.²³⁸ Women with Disabilities Australia, for example, told us that independent advocacy as a sector is ‘critically under-resourced for it to achieve its objectives and the desired human rights outcomes for all people with disability in Australia’, particularly as demand for advocacy services has risen in recent years.²³⁹

DANA reported in 2022 that working beyond means has been a norm in the advocacy sector for at least a decade, and that ‘advocacy organisations generally operate at (or above) capacity, maintaining advocacy supports on over-stretched and uncertain funding for the work they perform’.²⁴⁰ At Public hearing 5, Ms Fiona Downing, the Senior Disability Advocate of Disability Justice Australia Inc. described how rising demand for disability advocacy coupled with a shortfall in funding impacts disability advocates:

Across the state of Victoria there [are] a lot of advocates who are just burning out and we are getting great, experienced staff who can’t keep up with the workload and having the outlook on advocacy funding so poor, it is really difficult to keep people’s spirits up and to keep them engaged in their work.²⁴¹

We also heard about the particular challenges for advocacy services as a result of the COVID-19 pandemic. At Public hearing 5, we heard from one service that, because funding had not increased ‘in real terms’ for a decade, it was forced to close its waitlist for ‘months at a time’ during the pandemic. Other organisations also had to limit their advocacy work and focus on problems brought on by the pandemic, putting other issues aside because ‘the immediate crisis for people with disability has been so great’.²⁴² Following Public hearing 5, we found:

The regular funding provided to disability representative organisations by the Australian Government was insufficient to enable them to cope with the substantially increased demand for systemic and individual advocacy from the outset of the COVID-19 pandemic.²⁴³

Accordingly, we recommended the Australian Government should:

- immediately commit to providing supplementary funding to disability representative organisations for individual advocacy should there be a significant resurgence of COVID-19 in Australia²⁴⁴
- commit to providing supplementary funding to disability representative organisations for individual and systemic advocacy whenever a new pandemic or major emergency (such as a natural disaster) occurs. The commitment should include establishing an emergency fund that can be drawn on as soon as the need arises.²⁴⁵

The Australian Government supported these recommendations in principle. It stated it had provided additional funding and resources during the peak of COVID-19 to support people with disability, including through individual advocacy. It said it would consider the issue on a case-by-case basis in the event of a new pandemic or major emergency.²⁴⁶

Need for additional funding

Positive return on investment

In 2017, DANA commissioned a cost-benefit analysis of Australian independent advocacy agencies.²⁴⁷ The analysis found that 'independent disability advocacy delivers a substantial positive net economic benefit to Australia'.²⁴⁸ Benefits of independent advocacy included:²⁴⁹

- reduced costs for governments
- more productive employment for people with disability
- better educational outcomes for people with disability
- better health outcomes for people with disability
- better child protection outcomes for people with disability.

We also commissioned a cost-benefit analysis to confirm these results. This drew on the analysis commissioned by DANA and the work undertaken for the Royal Commission on the economic cost of violence, abuse, neglect and exploitation of people with disability.²⁵⁰ The cost-benefit analysis confirmed that independent advocacy services deliver a net benefit overall, and that advocacy is estimated to lead to the following economic benefits:²⁵¹

- increased life satisfaction for people who receive services
- reduced systemic failures and neglect that affect health and employment outcomes
- avoided costs to government.

Need for increased funding to meet unmet demand

At Public hearing 32, Counsel Assisting submitted there was a need for stable, increased funding for advocacy services in the context of engaging with service providers.²⁵² Following Public hearing 7, Counsel Assisting submitted there was a need for well-funded advocacy support in the context of inclusive education.²⁵³

Following Public hearing 32, Counsel Assisting submitted the Royal Commission consider recommending an urgent review by the Australian Government, in consultation with state and territory governments, people with disability, and advocacy organisations, of the funding arrangements for independent advocacy services and the implementation of measures to ensure greater, more stable funding for such services.²⁵⁴

The Australian Government disagreed an urgent review of funding arrangements for independent advocacy services is needed.²⁵⁵ The Australian Government did not accept that there is a lack of consistent funding for advocacy services. It did however agree demand for independent advocacy remains high.²⁵⁶

We commissioned independent analysis from Taylor Fry to determine the additional funding needed to meet unmet demand for independent advocacy.

The analysis did not consider demand for systemic advocacy. However, as we addressed earlier in this section, the 2022–23 October Budget doubled existing support for systemic disability advocacy.²⁵⁷

Before examining the analysis, it is important to define the following concepts:²⁵⁸

- ‘Met demand’ refers to clients who currently receive disability advocacy services.
- ‘Unmet demand’ refers to clients turned away by disability advocacy providers, primarily because they are insufficiently resourced.
- ‘Unmet need’ refers to the total pool of people who would benefit from advocacy services, including those unaware of the services or who face access barriers.

The analysis only considered met and unmet demand, as there is a lack of data on unmet need.²⁵⁹

The analysis estimated unmet demand based on two sets of survey data on the proportion of demand currently met by service providers:²⁶⁰

- a 2022 ‘Intake Project Final Report’ from DANA, which asked providers within each funding stream about the total number of people who had inquired for assistance and the number of people who were available to assist them
- the Draft Demand and Gap Analysis Report.²⁶¹

The analysis adopted the assumption that 75 per cent of demand for the NDAP is currently met.²⁶² This is consistent with the relevant statistic in the Draft Demand and Gap Report from the ASK Insight survey, which indicated that one in four people did not receive advocacy services in 2018–19.²⁶³

The analysis adopted the assumption that 65 percent of demand for the NDIS Appeals program is currently met. This lower figure is based on the DANA report, which indicated that a lower proportion of demand is met for the NDIS Appeals program.²⁶⁴

Taylor Fry reported that a limitation of both surveys was that they surveyed providers rather than people with disability. They noted this risks overcounting unmet demand, as a client turned away by one provider may obtain services elsewhere.²⁶⁵ They also said as funding for advocacy organisations is contingent on the existence of high demand for their services, ideally their estimates of demand would be validated against another source, such as a list of people with unmet demand. However, this was not possible with available data.²⁶⁶

We acknowledge these limitations and discuss in section 3.4 how data collection needs to be improved. Recommendation 6.22 calls upon the Australian Government and state and territory governments to use improved data to inform future, ongoing funding allocations and ensure that disability advocacy providers can meet demand for their services. However, we have taken into account the powerful evidence demonstrating the critical role of advocacy for people with disability and the extent of unmet demand for advocacy services. We have also taken into account that the Disability Royal Commission Individual Advocacy Support program will have ended by the time this *Final report* is published. We have concluded immediate action is needed to address the shortfall in funding.

Taylor Fry's analysis indicates total funding of \$40.9 million is required in 2024–25 to address unmet demand for the NDAP.²⁶⁷ Assuming program funding remains steady based on 2022–23 Budget commitments (\$24.3 million per annum, based on equally allocating \$73 million over three years), this means additional funding of \$16.6 million per annum is required to reach a total of \$40.9 million in 2024–25.²⁶⁸

The analysis indicates that total funding of \$27.4 million is required in 2024–25 to address unmet demand for the NDIS Appeals Program.²⁶⁹ Assuming that program funding remains steady based on 2022–23 Budget commitments (\$7.07 million per annum, based on equally allocating \$21.2 million across the three-year funding period²⁷⁰), this means additional funding of \$20.3 million is required to reach a total of \$27.4 million in 2024–25.

Recommendation 6.21 Additional funding for advocacy programs

- a. For the financial years 2024–25 and 2025–26, the Australian Government should commit additional funding of:
 - \$16.6 million per annum for the National Disability Advocacy Program
 - \$20.3 million per annum for the National Disability Insurance Scheme Appeals Program.

These amounts should be indexed to maintain their value in real terms from year to year.

- b. From 1 July 2026, the Australian Government should ensure long-term and stable funding for national disability advocacy programs to meet demand. This should be informed by improved data in line with Recommendation 6.22.
- c. From at least 1 July 2026, state and territory governments should ensure long-term and stable funding for disability advocacy programs in their jurisdictions to meet demand. This should be informed by improved data in line with Recommendation 6.22.

The total recommended additional funding of \$36.9 million per annum is less than the average \$37.6 million per annum that the Australian Government allocated to the Department of Social Services to fund advocacy, support and counselling services for people with disability and their carers engaging with or affected by the Disability Royal Commission between 2019–2020 and 2023–2024 (as discussed earlier in this section).

Ongoing funding estimates and the need for better data

The analysis from Taylor Fry projected demand for Commonwealth-funded advocacy, through both the NDAP and the NDIS Appeals Program, to 2027–28. The projections were based on the following assumptions:²⁷¹

- Demand for NDIS related advocacy will grow in line with the size of NDIS activity.
- Demand for non-NDIS related advocacy will grow in line with population growth for people with disability.

However, Taylor Fry's analysis notes there is uncertainty on estimates of future demand for disability advocacy, due to a lack of data. It recommends data collection be expanded to capture met and unmet demand.²⁷² We agree future demand projections are uncertain, and that any additional funding increases should be informed by a more robust dataset. We discuss these issues in section 3.4 and address them in Recommendations 6.21 and 6.22.

Taylor Fry also notes the lack of data on state and territory advocacy programs.²⁷³ The only available data is survey-based estimates, and the relative market share of states and territories covered in these surveys is uncertain.²⁷⁴ In light of this uncertainty and the lack of information about current state and territory funding commitments for disability advocacy, data collection should also be improved at the state and territory level to inform future funding. We discuss this in the next section and address it in Recommendation 6.22.

3.4. Data collection to inform future funding

Lack of data collection and supply-demand analysis

As part of the 2023–2025 NDAF, the Australian Government and all state and territory governments committed to:²⁷⁵

- ensuring the funding of disability advocacy is transparent, accountable and supports equitable outcomes, including identifying and addressing geographical coverage and services gaps
- collecting, using, and reporting of nationally consistent and evidence based data for administration and planning of disability advocacy and improvement of services systems.

At the national level, public reporting for the NDAP and the NDIS Appeals Program is limited to the number of people with disability receiving advocacy support and the total amount of funding

provided under each program.²⁷⁶ That is, publicly available data is limited to reporting on met demand. It does not quantify how many people sought help from advocacy services but were unable to access them.

At the state and territory level, there is a lack of publicly reported data in general. In a submission to the Royal Commission, Western Australia said an initial priority under its Disability Advocacy Program is to address the requirement for robust data collection.²⁷⁷

The Department of Social Services advised the Royal Commission:²⁷⁸

- there is no mechanism to exchange disability advocacy data between the Australian Government and state and territory governments
- the department does not hold data about the estimated number of clients supported by state or territory funded programs
- there is no formal joint mechanism between governments that will enable the identification of unmet demand, service areas or funding levels.

For advocacy organisations, the current lack of data makes it difficult to identify where their services are most needed. DANA noted the advocacy sector struggles with ‘the need for increased evidence of demand and need for advocacy, and [being able] to demonstrate the impact and positive outcomes achieved through independent advocacy’.²⁷⁹

In Public hearing 8, Ms Dana Clarke, CEO of the Burran Dalai Aboriginal Commission, explained that while a lot of data on First Nations people with disability is gathered by governments, it is collected without any collaboration from First Nations people, and often it is not provided to First Nations advocacy organisations.²⁸⁰

Improving data collection on met and unmet demand

Taylor Fry’s analysis recommended any revisions to both Australian Government and state and territory government advocacy funding models be supported by more consistent reporting, including monitoring of changes in the level of met and unmet demand over time.²⁸¹

Taylor Fry reported:

Funding estimates could be disaggregated by demographic factors such as clients from First Nations or cultural and linguistically diverse (CALD) background[s], who may require higher funding to meet their needs.²⁸²

Taylor Fry recommended funding models for advocacy programs (at both the national and state and territory levels) be ‘supported by a strong process of regular public reporting’, including:²⁸³

-
- comparison of met and unmet demand against expectations
 - analysis of the drivers of unmet demand
 - an assessment of key gaps (for example, by type of advocacy services and geography).

Taylor Fry also recommended ‘governments consider the value of improved data collection’ to more accurately estimate ‘met demand, unmet demand and the profile of services requested’.²⁸⁴

We agree with Taylor Fry’s observations and recommendations regarding the current lack of data.

We consider, at a minimum, all governments should collect and report on data on met and unmet demand for disability advocacy programs. As Recommendation 6.21 proposes, they should use this data to inform future funding allocations to meet demand. This data should:

- be collected and published on an annual basis
- include demographic indicators that show geographic location, First Nations and culturally and linguistically diverse status
- identify, where possible, whether a request for disability advocacy is from or concerns a person with disability who lives in supported accommodation or is in prison or juvenile detention.

Data collected about First Nations people and service providers should be published and disseminated in a way that supports the principle of data sovereignty.

Prior to the release of the 2023–2025 NDAF, the Department of Social Services advised that the NDAF and the Disability Advocacy Work Plan will provide a mechanism to improve alignment of disability advocacy approaches and better coordinate available funding.²⁸⁵

The Disability Advocacy Work Plan includes six priority work areas, including:

- work area 2 – *explore existing data collection practises across jurisdictions*, which includes participating jurisdictions working together to understand current data collection and aiming to identify and agree a disability advocacy core dataset²⁸⁶
- work area 3 – *improving service delivery*, which includes a mapping exercise to identify where current disability advocacy services are available²⁸⁷
- work area 5 – *better coordination of funding*, which aims to identify possible improvements to the coordination of available funding across participating jurisdictions.²⁸⁸

Given the current lack of data collection and reporting, we consider an additional priority work area should be improving data collection on met and unmet demand for disability advocacy. Work area 3 may assist this additional work area.

Recommendation 6.22 Improved data collection and reporting on met and unmet demand for disability advocacy

The Australian Government and state and territory governments should improve data collection and reporting on met and unmet demand for disability advocacy within their jurisdiction.

At a minimum, this data should:

- be collected and published on an annual basis
- include demographic indicators that show geographic location, First Nations and culturally and linguistically diverse status
- identify, where possible, whether a request for disability advocacy is from or concerns a person with disability who lives in supported accommodation or is in prison or juvenile detention.

This data should be collected and reported on an ongoing basis.

The Australian Government and state and territory governments should include data collection and reporting as a priority work area in the Disability Advocacy Work Plan associated with the 2023–2025 National Disability Advocacy Framework, and progress this as part of future National Disability Advocacy Frameworks or equivalents.

The Australian Government and state and territory governments should work together to ensure consistent definitions and methodologies allowing comparisons across jurisdictions and trends over time.

Publication of the data should commence no later than 1 July 2026.

3.5. Cultural safety

A broad range of people with disability need and use disability advocacy. These include people with disability who may be First Nations, from culturally and linguistically diverse backgrounds, LGBTIQ+, women, young people, older people or any combination of these. We have heard, in particular, about the challenges First Nations, culturally and linguistically diverse and LGBTIQ+ people with disability experience in accessing culturally safe disability advocacy.

Culturally safe advocacy

First Nations people with disability

Ongoing trauma and distrust

First Nations people with disability experience ongoing trauma, particularly when dealing with public systems and services. Evidence at Public hearing 25, ‘The operation of the NDIS for

First Nations people with disability in remote and very remote communities' highlighted some challenges that First Nations people with disability face in accessing the NDIS and disability services in remote communities.²⁸⁹ Barriers include:

- distrust of government institutions because of the history of child removal²⁹⁰
- issues faced when developing NDIS plans²⁹¹ and when seeking to access culturally safe and appropriate supports and services²⁹²
- the high cost of delivering services in remote and very remote communities.²⁹³

At Public hearing 4, the Royal Commission heard from Ms Narelle Reynolds, a First Nations woman who acts as an advocate for her son and other people with disability in her community. She demonstrated how the intersecting types of inequality that First Nations people with disability face put them more at risk of having their rights and autonomy infringed:

For me, being Aboriginal on top of being a mother of children with intellectual disability is a double whammy. Being black and fighting through the health system is one thing, but fighting for sons with intellectual disability is another.²⁹⁴

At Public hearing 8, we heard that early legal and non-legal advocacy and outreach is particularly important for First Nations people with disability and their supporters, given their history of being over-policed and having children removed from their families.²⁹⁵ Mr Damien Griffis, CEO of the First People's Disability Network, said:

The situation for many First Nations people with disability in regional and remote Australia, to be blunt, is one of abject poverty. The only way to get meaningful support to our community members out there is to go see them on country and try and seek support.²⁹⁶

We discuss the experiences of First Nations people with disability in more detail in Volume 9, *First Nations people with disability*.

Lack of First Nations led disability advocacy services

Advocacy services designed and run by First Nations people with disability can be sources of information and access to culturally safe and appropriate services and supports. Aboriginal Community Controlled Organisations, such as legal and health advocacy services, can provide referrals to NDIS programs that are 'culturally suitable for First Nations families and integrate western approaches with First Nations methodologies and knowledges'.²⁹⁷

Skilled independent, non-legal advocates can provide vital support to First Nations parents with psychosocial or cognitive disability. The most effective non-legal advocates are likely to be those who are culturally competent and disability aware.²⁹⁸ First Nations community-controlled organisations, or disability-specific advocacy organisations, should be preferred as a matter of course for First Nations people with disability, including parents with disability.

Though the demand for disability advocacy among First Nations people with disability is high,²⁹⁹ the numbers of First Nations disability advocacy organisations that service this cohort are low.³⁰⁰ Mr Griffiths gave evidence at Public hearing 18, ‘The human rights of people with disability and making the *Convention on the Rights of Persons with Disabilities* a reality in Australian law, policies and practices’. He said culturally sensitive and appropriate advocacy is so in demand among First Nations people with disability that ‘it’s impossible to meet individual advocacy needs’.³⁰¹

In Public hearing 11 the Royal Commission heard evidence that ‘only Aboriginal Community Controlled Organisations can be truly culturally safe’.³⁰² Ms Cheryl Axleby, from Aboriginal and Torres Strait Islander Legal Services, told us:

‘Cultural safety’ is determined by the experience of the people who use that service, in this case Aboriginal and Torres Strait Islander people. There are many facets to what makes an Aboriginal or Torres Strait Islander person feel culturally safe, but there is not a definitive list, because cultural safety varies for different people and places. In the context of the justice system, cultural safety for Aboriginal and Torres Strait Islander people includes: feeling heard, believed and understood, including in your own language; feeling confident to share your story; being able to seek service without fear of mistreatment, repercussions or misunderstanding of cultural needs; not having to defend your experience of systemic or cultural barriers or discrimination, knowing that your legal representative will do their best to overcome those barriers to get you a fair hearing and outcome.³⁰³

Volume 9, *First Nations people with disability* discusses the importance of cultural safety for First Nations people with disability in greater detail and makes recommendations for structural reform to ensure culturally safe and responsive services.

People from culturally and linguistically diverse backgrounds

We also heard about the importance of advocacy for people from culturally and linguistically diverse backgrounds.

Mr Dominic Hồng Đức Golding, a policy and project officer at the National Ethnic Disability Alliance gave evidence in Public hearing 9, ‘Pathways and barriers to open employment for people with disability’. He spoke about the value of advocacy specialised for and conducted by people with disability from culturally and linguistically diverse backgrounds:

There is a gentleman who was a recently arrived refugee. He needed assistive technology to be able to read the computer, but he also needed some voice-activated software systems ... his normal job settlement worker told him to approach Vision Australia ... and he got rejected back because they said that they didn’t understand him because he didn’t speak English well enough. So I also encouraged to explain to the person, this is his background, this is what he needs, and this is what he requires ... he himself could not self-advocate for himself because of his language barrier.

But once the worker understood that he could get support and then say to the employer, 'I have this equipment, assistive technologies available for me, I'm quite happy to seek employment'.³⁰⁴

At Public hearing 29, Ms Kylie Scoullar, General Manager for Direct Services at Foundation House, gave evidence on the specialised nature of providing advocacy to people from culturally and linguistically diverse backgrounds who have complex trauma from experiences of war, torture and displacement. Ms Scoullar described the importance of trauma-informed and culturally responsive approaches. She explained:

unless the system is trauma-informed, people from refugee backgrounds are unlikely to access those services, which means, in a sense, there's systemic neglect.³⁰⁵

'Cindy' is an advocate for people with disability from refugee migrant backgrounds. She gave evidence at Public hearing 29 about the importance of having diverse representation within the advocacy sector. She said that the advocacy sector 'is not very diverse in the sense of cultural diversity' and therefore does not address intersecting identities together in a meaningful way.³⁰⁶ Greater diversity in the advocacy sector would mean that people with disability can see themselves represented among their advocates and work with someone who understands them.³⁰⁷ Without this, many people with disability can feel alienated from Australia's disability service system.³⁰⁸ In the same hearing, Ms Simbi stated:

people connect more with a service if there is somebody from ... [a] culturally linguistically diverse background working in that organisation or the person has a disability or is a parent with a disability.³⁰⁹

But she said this is currently 'a big gap in the community'.³¹⁰

At Public Hearing 30, Ms Christine Grace described how Kin Disability Advocacy ensures cultural safety by engaging interpreters so that people 'tell their story to our staff in their first language'.³¹¹ Ms Grace also emphasised the importance of recruiting staff from cultures and backgrounds of the clients they engage with.³¹²

In a submission to the Royal Commission, Multicultural Australia described an example of a migrant with disability, who was referred to an advocacy service when they were not receiving the services outlined in their NDIS package. Their advocate had the case reviewed. This revealed that their support coordinator was billing for services without linking the client to supports.³¹³ Multicultural Australia also gave an example of a young girl with disability who arrived in Australia with her family as a refugee and was only able to gain NDIS supports though the assistance of advocates.³¹⁴

In these ways, advocacy can support individuals with disability from culturally and linguistically diverse backgrounds to receive the supports to which they are entitled and enable them to access 'meaningful community participation and inclusion'.³¹⁵

Funding and demand for specialist advocacy services

The NDAP and the NDIS Appeals Program fund 59 providers across Australia.³¹⁶ This includes specialist providers for First Nations people and people from culturally and linguistically diverse backgrounds. Generalist advocacy providers also provide services to these client groups.³¹⁷ Since July 2018, the Australian Government has met the cost of interpreting services that advocacy providers use when they support people from culturally and linguistically diverse backgrounds. The Department of Home Affairs' Translating and Interpreting Service delivers these services.³¹⁸

As noted above, the only publicly available data for the NDAP and the NDIS Appeals Program is the annual number of clients and total program funding. However, information we obtained under notice from the Department of Social Services provides an insight into the types of data that could be collected and used to better align funding allocation to areas of need.

Table 6.3.3 provides an overview of the total number of clients in 2021–22, including the number of First Nations people and culturally and linguistically diverse (CALD) people.³¹⁹

Table 6.3.3 Number of clients served by national advocacy programs in 2021–22

Program	Funding (\$m)	Total clients	First Nations clients	CALD clients
NDAP	\$24.75 m	13,441	1,469	802
NDIS Appeals	\$15.40 m	3,819	292	125

Source: Australian Government Department of Social Services (2023). The source does not define culturally and linguistically diverse clients or First Nations clients.

In 2021–22, there were two First Nations specific services funded under the NDAP and the NDIS Appeals Program. One was in New South Wales and the other in the Northern Territory and South Australia.³²⁰ These providers served a total of 274 clients in 2021–22. Of these clients, 270 (99 per cent) identified as First Nations.³²¹

In the same year, there were three services funded specifically for culturally and linguistically diverse people with disability. These were based in Victoria, Western Australia and New South Wales.³²² They served a total of 1,339 clients. Of these clients, 559 (42 per cent) were from culturally and linguistically diverse backgrounds. In the same period, 37 per cent of all NDAP clients from culturally and linguistically diverse backgrounds accessed advocacy services from generalist providers under the NDAP.³²³ The Department of Social Services did not provide equivalent data for the NDIS Appeals program or for the number of First Nations clients served by generalist providers under either program.

Table 6.3.4 shows the amount of funding to specialist First Nations and culturally and linguistically diverse advocacy providers.³²⁴

Table 6.3.4 Funding for specialist national advocacy providers in 2021–22

Program	Funding (\$m)	First Nations providers (\$m)	CALD providers (\$m)
NDAP	\$24.75 m	\$0.46 m	\$1.6 m
NDIS Appeals	\$15.40 m	\$0.2 m	\$0.52 m

Source: Australian Government Department of Social Services (2023).

These two datasets demonstrate a significant disparity between the proportion of First Nations clients accessing national advocacy programs and the proportion of funding allocated to First Nations specialist providers. In 2021–22:

- First Nations clients comprised 11 per cent of total NDAP clients, and First Nations specialist providers received 1.9 per cent of total NDAP funding.
- First Nations clients comprised 7.6 per cent of total NDIS Appeals clients, and First Nations specialist providers received 1.3 per cent of total NDIS Appeals funding.

In the same year, the proportion of clients from culturally and linguistically diverse backgrounds accessing the NDAP and the NDIS Appeals Program (6 per cent and 3.3 per cent respectively) was broadly in line with the total funding allocated to specialist providers for this cohort (6.5 per cent and 3.4 per cent respectively).

Based on Department of Social Services data and evidence presented to the Royal Commission, there is a high level of unmet need for First Nations specialist advocacy services. It is reasonable to conclude that a large number of First Nations people with disability are relying on generalist advocacy providers as they are unable to access specialist services. This can be attributed to the funding disparity outlined above, as well as the limited geographic coverage of the two First Nations specialist services.

This analysis underscores the importance of ensuring advocacy program funding models are informed by robust data, and ensuring generalist advocacy providers ensure culturally safe and accessible services (see Recommendation 6.23).

LGBTIQA+ people with disability

In information submitted to the Royal Commission, DANA noted that no LGBTIQA+ organisations receive ongoing funding to represent the specific concerns of LGBTIQA+ people with disability.³²⁵ Moreover, DANA submitted there needs to be development of training to support advocacy organisations to meet the needs of people with disability regardless of sexuality or gender identity.³²⁶

In response to the *Issues paper on violence and abuse of people with disability at home*, WWILD Sexual Violence Prevention submitted that LGBTIQA+ people with disability face

‘unique aspects of violence’ because of the combination of ableism and ongoing stigma they experience.³²⁷ WWILD stated that this is compounded by the ‘lack of clear and obvious support and celebration of diversity’ in the disability sector. This puts LGBTIQ+ people with disability at greater risk of experiencing violence, abuse, neglect and exploitation.³²⁸ Disability advocacy that understands the nuances of LGBTIQ+ identity and the risks LGBTIQ+ people with disability face is crucial to safeguarding their rights and autonomy.

Cultural safety training as part of sector capacity building

The NSW Ageing and Disability Commission’s *Review into disability advocacy in NSW* (2019) recognised the need for capacity building in the advocacy sector. The review stated that ‘there is identifiable need to develop the competency, capacity and capability of the disability sector and its workforce’. It noted that this included the need to develop ‘cultural competencies’.³²⁹ The review recommended the establishment of a Centre for Disability Advocacy Development designed to:³³⁰

- enhance and improve the development of high quality, sustainable disability advocacy services
- provide community information about access to disability advocacy
- foster collaboration and innovation among disability advocacy providers
- support self-advocacy initiatives.

The proposed activities for this centre also included data gathering, resource development, development of a code of practice for disability advocacy providers, and review of sector-wide performance and outcomes.³³¹

The New South Wales Government has yet to respond to the recommendations in the review.

At the national level, the Australian Government has committed \$650,000 per year for three years to establish a ‘program management centre’, now referred to as the National Centre for Disability Advocacy.³³² This is part of the \$9.9 million committed in the 2022–23 Budget to support the implementation of the ADS.³³³ The centre’s purpose is to improve access to, and the quality of, individual advocacy services, including by introducing best practice service delivery models.³³⁴

The National Centre for Disability Advocacy will be led by DANA. DANA told the Royal Commission that funding to DANA for the National Centre for Disability Advocacy ‘provides an opportunity to build much needed sector capacity over the next few years through training and building communities of practice’.³³⁵

We support the Australian Government’s commitments to sector capacity building made to date. However, they do not specifically recognise the need to deliver culturally safe advocacy services, recognised under the 2023–2025 NDAF. The 2023–2025 NDAF includes principles focusing on ‘Inclusion and Accessibility for First Nations People with Disability’

and 'Understanding of and Respect for Intersectionality and Diversity'.³³⁶ The 2023–2025 NDAF states it will contribute to a range of outcomes, including:³³⁷

- First Nations peoples with disability have a greater say in how advocacy is designed and delivered; have access to culturally and linguistically appropriate, and culturally safe, disability advocacy, including access to community controlled organisations delivering disability advocacy; and have access to, and the capability to use, locally-relevant data and information
- all people with disability, including people with disability from culturally and linguistically diverse communities, have access to culturally and linguistically appropriate, and culturally safe, disability advocacy that features the engagement and input of relevant local communities.

While there are some specialist providers for First Nations people and people from culturally and linguistically diverse communities, data received under notice from the Department of Social Services demonstrates a high degree of reliance on generalist advocacy services. They need to enhance their ability to provide safe and effective advocacy for First Nations people, people from culturally and linguistically diverse communities, and LGBTIQ+ people.

To address this, sector capacity building should include training to improve cultural competency and cultural safety in generalist advocacy services, supported by appropriate funding. First Nations, culturally and linguistically diverse and LGBTIQ+ organisations should lead these training activities.

The Disability Advocacy Work Plan associated with the 2023–2025 NDAF includes as a priority work area 'increasing culturally appropriate and accessible advocacy services for First Nations people with disability'. It states:

There is a need for improved access to culturally safe advocacy for First Nations People with disability. This project will identify ways to increase access to disability advocacy including by increasing training opportunities and resources to improve cultural competency for disability advocacy services and/or projects to enable First Nations people to become leaders and advocates in disability.³³⁸

We welcome this development. However, we recommend the work plan be amended to make similar provision for people from culturally and linguistically diverse backgrounds with disability and LGBTIQ+ people with disability.

In Volume 9, *First Nations people with disability* we recommend the development of an agreed set of cultural safety standards. Once these are developed, the Australian Government and state and territory governments should consider these standards as part of efforts to improve cultural safety in generalist advocacy services.

Generalist disability advocacy services under the NDAP should also consider steps for continuously improving their provision of culturally safe advocacy. For example, they could use targeted measures to proactively seek and respond to feedback from First Nations, culturally

and linguistically diverse and LGBTIQ+ people with disability to whom they provide advocacy. They could also publish information on their websites and produce public-facing materials that describe how they practise cultural safety and how they have assisted First Nations, culturally and linguistically diverse and LGBTIQ+ people with disability in the past.

Recommendation 6.23 Culturally safe disability advocacy

The Disability Advocacy Work Plan associated with the 2023–2025 National Disability Advocacy Framework should be amended to include priority work areas on increasing culturally appropriate and accessible advocacy services for people with disability from culturally and linguistically diverse backgrounds and LGBTIQ+ people with disability. Efforts under these priority work areas, and the priority work area on increasing culturally appropriate and accessible advocacy services for First Nations people with disability, should include training led by First Nations, culturally and linguistically diverse and LGBTIQ+ people with disability and their representative organisations.

This work should be progressed as part of future National Disability Advocacy Frameworks or equivalents.

3.6. Informal supports

Informal supports, also known as informal safeguards or natural safeguards, are the social support networks that provide protection for people with disability by increasing connections, relationships and visibility in the wider community.

Informal supports complement formal safeguards and are a preventative measure against the risks of violence, abuse, neglect and exploitation.³³⁹ Enabling and supporting interpersonal relationships is an integral component to building an inclusive Australia.

When people with disability are socially isolated and marginalised, informal supports are particularly important.³⁴⁰ Enhancing community connections and building a network of relationships can assist people with disability to identify and speak up about experiences of violence, abuse neglect and exploitation.³⁴¹

The ADS recognises the ‘vitally important’ role of informal supports for people with disability as a priority issue:

The support provided in these close relationships can often be one of mutual support ... In addition to providing practical and emotional support, those providing informal support can represent the interests and rights of the person they support ... Acknowledging and supporting individuals and organisations who provide informal care and support can increase the participation of people with disability in community life.³⁴²

We recognise that family, informal carers and people in close personal relationships may also perpetrate violence, abuse, neglect and exploitation. These issues are addressed in Volume 8, *Criminal Justice and people with disability*. Volume 10 also examines resident-to-resident violence in supported accommodation.

Social isolation, supported accommodation and homelessness

The Royal Commission has heard about the critical role of informal supports for people with disability who are experiencing social isolation. Informal supports are particularly important for people in supported accommodation, living alone or experiencing homelessness.

Strong relationships and social support networks can prevent harm and counter social isolation for people living in group homes or living alone.³⁴³ At Public hearing 3, we heard how a network of relationships can improve the safety of people with disability and prevent violence, abuse, neglect and exploitation in these settings.³⁴⁴ Evidence demonstrated that being known, being understood and having trusted relationships are key safety strategies.³⁴⁵ Families and supporters are well placed to monitor the provision of disability services and to identify issues of potential or developing neglect.

Professor Christine Bigby, Director of Latrobe Living with Disability Research Centre, emphasised the need for people to build connections with others outside the service system.³⁴⁶ This is supported by the Safeguarding Task Force in South Australia, which found that an 'extra pair of eyes' can reduce the risk of violence, abuse, neglect or exploitation. The task force recognised that the best safeguard for people with disability living alone is to have relatives and friends who can readily provide support if the person with disability faces a risk of harm.³⁴⁷

However, in supported accommodation, people with disability can face barriers to building these informal support networks. In particular, people with disability in supported accommodation may have limited access to the community and social support networks.³⁴⁸ At Public hearing 3, Professor Bigby said 'staff perceived their purpose for being there as being to look after people' instead of 'to build relationships and participate in the community'.³⁴⁹

Building and maintaining informal supports can also be challenging for people with disability who are experiencing homelessness. Evidence in Public hearing 26 revealed that people with disability can become disconnected from family and community when they become homeless or face a period of crisis in housing. In particular, witnesses said that people who do not have access to appropriate homelessness services and supports may need to be relocated, and this can disrupt their established social support networks.³⁵⁰

Witnesses told us that stable housing near friends, partners, families and supporters, during times of transition and crisis, minimises harm and helps prevent isolation. One witness, 'Claudia' spoke about the importance of her relationship with her partner, 'Jean', while experiencing homelessness. She described Jean as her 'anchor' during these times.³⁵¹ Living in close proximity to Jean has ensured Claudia feels supported.³⁵²

The challenges and barriers associated with living in group homes and for people experiencing homelessness are further discussed in Volume 7.

Peer support

... peer support, peer education, and advocacy [are] the fundamental building blocks to addressing disempowerment ...³⁵³

‘Peer support’ is support to people with disability from others with disability. It is centred on relationships and sharing experiences. Peer support can help people with disability to access advocacy (discussed in the previous section), education, counselling, mediation and mutual support.³⁵⁴ Peer support can range from face-to-face peer support meetings, to one-on-one peer mentoring, larger structured workshops, and online and phone-based approaches.³⁵⁵ We heard from a number of witnesses about the value of peer support workshops and mentoring programs to teach people with disability how to ‘stand up’ for their rights.³⁵⁶

Peer support also leads to increased social connections and networks.³⁵⁷ For example, Ms Sherrie Beaver, who is Manager, Grants & Projects for Expression Australia, gave evidence about the Rainbow Project at Public hearing 31.³⁵⁸ Events, ranging from social gatherings to seminars on sexuality and health, built individual capacity for Deaf LGBTIQ+ people by increasing social connections and information sharing.³⁵⁹ The Rainbow Project is funded through the Information, Linkages and Capacity Building Program discussed below.³⁶⁰

We heard how online peer support opportunities can promote social engagement. At Public hearing 28, Ms Maree Jenner, Vice President of the Short Statured People’s Association of Australia (SSPA), spoke about the operation of online peer support groups.³⁶¹ In 2020, as a result of online engagement, SSPA was able to deliver a virtual convention where members contributed experiences to support the organisation’s systemic advocacy.³⁶² Evidence on the role and importance of peer-support programs is further reinforced by research on enhancing NDIS engagement for people with psychosocial disability who are at risk of homelessness.³⁶³ The study stated that relationship-based support and peer leadership are central elements that help to engage people who may be marginalised and not connected to publicly funded disability and other social support.³⁶⁴

Similarly, the consultation for the National Disability Insurance Scheme Quality and Safeguarding Framework found many stakeholders reported peer support networks have important functions and help people to build an understanding of rights, information and report issues when something goes wrong.³⁶⁵

At Public hearing 31, Ms Angel Dixon OAM, a lived experience witness, advocate and researcher and Associate Professor Dr Paul Harpur, University of Queensland, told the Royal Commission that peer support can have a 'huge impact' and contribute to 'upskilling' of people with disability.³⁶⁶ Greater investment in peer leadership programs can enable people with disability to engage in community initiatives such as emergency preparedness.³⁶⁷ Evidence and information before the Royal Commission has also shown that peer mentoring roles can help to overcome systemic barriers to open employment and create valuable training opportunities for people with disability.³⁶⁸

Research commissioned by the NDIS on peer support practice discussed the need for increased funding to engage with marginalised groups, particularly those who are socially isolated.³⁶⁹ A key finding of the review was the resource intensive nature of peer support, especially when it involves engaging with marginalised groups.³⁷⁰ Once established, groups needed ongoing funding to continue their operations. However, they often face funding uncertainties that create difficulties for future planning and practice development.³⁷¹

Funding

Funding under the NDAP, discussed in section 3.3, includes funding for advocacy organisations to deliver citizen advocacy and self-advocacy.³⁷² These forms of advocacy can also build informal supports networks. Recommendations 6.21 and 6.22 recommend increased funding for the NDAP in the immediate term and on an ongoing basis, based on improved data collection.

The Information, Linkages and Capacity Building program (ILC) 'provides funding to organisations to deliver projects in the community that benefit all Australians with disability, their carers and families'.³⁷³ In August 2015, the former COAG Disability Reform Council endorsed the ILC Policy Framework, which recognises that there was 'an opportunity through the ILC for the NDIS to support people with disability to lead peer support and promote self-advocacy amongst peers'.³⁷⁴

There are four program streams in the ILC. One of these streams is the Individual Capacity Building Program. A key aim of the Individual Capacity Building Program is to enable systemic nationwide access to peer support, mentoring and other skills building for people with disability, carers and families.³⁷⁵

In 2021, the Department of Social Services commissioned analysis of the gaps and unmet needs in the program. The analysis included interviews and surveys of organisations who were funded under the program or from the disability sector.³⁷⁶ Survey and interview respondents considered that individual capacity building is a 'high value and high return investment', as its benefits and impacts 'continue to accrue and ripple out into many life areas'.³⁷⁷

The analysis found:³⁷⁸

- The groups that are most often supported by projects are ‘all disability’, intellectual disability, autism and psychosocial disability. These groups were also the ones that interviewees and survey respondents most identified as the ones most in need of support.
- The ‘dominant theme’ of projects was capacity building. The largest area of investment was social inclusion and choice/empowerment activities.
- An important role exists for organisations ‘that are independent of commercial service provision and are peer-led, to provide information and develop the skills and knowledge of people with disability and their family members’.³⁷⁹
- Respondents also noted that the ILC program is delivered in an environment of ‘extremely precarious funding with significant gaps in coverage’.³⁸⁰

The independent review of the NDIS is considering the effectiveness of the ILC program.³⁸¹ This is further discussed in Volume 5, *Governing for Inclusion*.

State and territory governments also have a critical role to play in funding organisations that assist people with disability to develop informal support networks. This is in addition to their role in funding advocacy organisations as discussed in section 3.3. States and territories may fund volunteer networks and organisations that run peer-support programs. For example, the ‘Disability self-help grants program’ provides grants up to \$10,000 to support Victorian disability self-help groups, including to encourage a network of community peer support.³⁸²

However, there is limited publicly available information on the funding states and territories provide to organisations working to build informal supports among people with disability, through activities like peer support. We encourage states and territories to review the funding they provide to organisations that engage in peer support and assist people with disability to build networks of trusted supporters. States and territories should ensure this funding reflects the important role informal supports play in preventing violence against, and abuse, neglect and exploitation of people with disability.

We make other recommendations to better recognise and enhance informal supports for people with disability:

- Recommendation 6.6 in Chapter 2, ‘Supported decision-making’ recommends 10 supported decision-making principles. Principle 4 – Recognition of informal supporters and advocates provides that the role of informal supporters and supporter networks that provide for support for decision-making should be acknowledged.
- Recommendation 6.15 in Chapter 2, ‘Supported decision-making’ recommends that the national standards for public advocates, public guardians and public trustees include a new standard on representatives facilitating connections with informal supporters.

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- Volume 7 recommends that the NDIS Commission prioritise implementation of the Own Motion Inquiry into Aspects of Supported Accommodation – Action Plan, including strengthening how disability providers implement models of practice to ensure that people with disability living in group homes are actively supported to have opportunities for greater social interaction, community participation and inclusion.

We also acknowledge, by their nature, informal supports are organic and community driven. Our recommendations in various volumes of this *Final report* seek to promote a more inclusive society where opportunities will naturally arise for people with disability to be included in the community and build connections and friendships with their neighbours and peers.

Endnotes

- 1 *Letters Patent* (Cth), 4 April 2019 amended 13 September 2019, (h).
- 2 Australian Government Department of Social Services, National Disability Advocacy Framework 2023-25, June 2023, p 3.
- 3 Transcript, Margherita Coppolino, Public hearing 31, 14 December 2022, P-192 [44–47], P-193 [6–7].
- 4 Exhibit 30-099, ‘Statement of Dr Colleen Pearce’, 5 November 2022, at [274].
- 5 *National Disability Insurance Scheme Act 2013* (Cth) s 4(13).
- 6 *National Disability Insurance Scheme Act 2013* (Cth) s 4(13).
- 7 *Disability Services Act 1986* (Cth) s 7(a).
- 8 Australian Government Department of Social Services, National Disability Advocacy Framework 2023-25, June 2023, p 2.
- 9 Australian Government Department of Social Services, National Disability Advocacy Framework 2023-25, June 2023, p 3.
- 10 Australian Government Department of Social Services, Disability Advocacy Work Plan 2023-2025, June 2023, p 2.
- 11 Australian Human Rights Commission, *A future without violence: Quality, safeguarding and oversight to prevent and address violence against people with disability in institutional settings*, Report, June 2018, pp 39–40; Victorian Ombudsman, *Reporting and investigation of allegations of abuse in the disability sector: Phase 2 – incident reporting*, Investigation report, December 2015, pp 84 [304], 86 [327], 92 [327]; The Social Deck, Report prepared for the Australian Government Department of Social Services, *Right to opportunity: Consultation report to help shape the next national disability strategy*, Report, December 2019, pp 21, 26–27.
- 12 New South Wales Ombudsman, *Abuse and neglect of vulnerable adults in NSW – the need for action*, Special report to Parliament under section 31 of the Ombudsman Act 1974 (NSW), November 2018, p 31.
- 13 New South Wales Ageing and Disability Commissioner, *Review into disability advocacy in NSW*, Report, December 2019, p 71.
- 14 New South Wales Ageing and Disability Commissioner, *Review into disability advocacy in NSW*, Report, December 2019, p 68.
- 15 Australian Government Department of Social Services, National Disability Advocacy Framework 2023-25, June 2023, p 3.
- 16 Australian Government Department of Social Services, National Disability Advocacy Program Operational Guidelines, February 2018, p 12.
- 17 Transcript, ‘Ashleigh’, Public hearing 28, 12 October 2022, P-203 [30–34]; See also: Transcript, ‘Claudia’, Public hearing 26, 30 August 2022, P-152 [41–49], P-162 [12–16]; Transcript, Julie Butler and Cathy Dowsett (Counsel Assisting), Public hearing 28, 12 October 2022, P-208 [23–37]; Transcript, Jane Rosengrave, Public hearing 3, 2 December 2019, P-59 [15–17]; Transcript, Kevin Stone, Public hearing 3, 4 December 2019, P-167 [19–21]; Transcript, Pauline Williams, Public hearing 3, 5 December 2019, P-353 [31–40].
- 18 Transcript, Robert Strike, Public hearing 4, 28 February 2020, P-868–869; Exhibit 4-1, ‘Statement of Kylie Scott’, 7 February 2020, at [36–40].
- 19 Exhibit 4-1, ‘Statement of Kylie Scott’, 7 February 2020, at [38].
- 20 Exhibit 28-036, ‘Statement of Carly Findlay’, 28 September 2022, at [12].
- 21 Exhibit 28-036, ‘Statement of Carly Findlay’, 28 September 2022, at [119].
- 22 Transcript, Natalie Sandon-Stanhope, Public hearing 29, 24 October 2022, P-22 [26–30], P-22 [42] – P-23 [3].
- 23 Transcript, Gillian Mahony (Counsel Assisting) and Natalie Sandon-Stanhope, Public hearing 29, 24 October 2022, P-23 [5–8].
- 24 Transcript, Gillian Mahony (Counsel Assisting) and Natalie Sandon-Stanhope, Public hearing 29, 24 October 2022, P-23 [42]–P-25 [4].
- 25 Transcript, Anaab Rooble, Public hearing 29, 26 October 2022, P-241 [31–37], P-243 [8–12].
- 26 Transcript, Esther Simbi, Public hearing 29, 28 October 2022, P-334 [17–30], P-346 [4–9].
- 27 Transcript, Esther Simbi, Public hearing 29, 28 October 2022, P-342 [2–22].
- 28 Exhibit 29-021, ‘Statement of Esther Simbi’, 12 October 2022, at [31–32].

29 Transcript, Jen Hargrave, Public hearing 17, 13 October 2021, P-36 [2–7], P-42 [20–24];
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30 Transcript, Margherita Coppolino, Public hearing 31, 14 December 2022, P-196 [11–15].

31 Transcript, Margherita Coppolino, Public hearing 31, 14 December 2022, P-195 [2–5].

32 Transcript, Kobie Hicks, Public hearing 17, 30 March 2022, P-175 [19–20].

33 Exhibit 30-073, 'Statement of John O'Donnell', 27 October 2022, at [9]; Transcript, Kate Eastman
 (Counsel Assisting) and John O'Donnell, Public hearing 30, 23 November 2022, P-261 [39] –
 P-262 [2].

34 Transcript, John O'Donnell, Public hearing 30, 23 November 2022, P-262 [4–8].

35 Exhibit 30-073, 'Statement of John O'Donnell', 27 October 2022, at [10].

36 Exhibit 30-073, 'Statement of John O'Donnell', 27 October 2022, at [72]; See also: Transcript,
 Kate Eastman (Counsel Assisting) and John O'Donnell, Public hearing 30, 23 November 2022,
 P-281 [42] – P-282 [8].

37 Transcript, Julie Butler, Public hearing 28, 12 October 2022, P-208 [18–20].

38 Transcript, Julie Butler, Public hearing 28, 12 October 2022, P-208 [35–37], P-211 [38–41].

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40 Transcript, Sarah Forbes, Public hearing 3, 5 December 2019, P-346 [5–9].

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42 Exhibit 4-1, 'Statement of Kylie Scott', 7 February 2020, P-22 [26–29]; Transcript, Kate Eastman
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43 Transcript, Margherita Coppolino, Public hearing 31, 14 December 2022, P-192 [45–46].

44 Transcript, Margherita Coppolino, Public hearing 31, 14 December 2022, P-192 [46–47].

45 Transcript, Margherita Coppolino, Public hearing 31, 14 December 2022, P-193 [15–16].

46 Transcript, Stephen Leeder, Public hearing 4, 20 February 2020, P-160 [28–30].

47 Transcript, Robert Strike, Public hearing 4, 28 February 2020, P-874 [11–13].

48 Transcript, Toni Mitchell, Public hearing 4, 19 February 2020, P-117 [11–17].

49 Transcript, Toni Mitchell, Public hearing 4, 19 February 2020, P-122 [3–13]; Exhibit 4-25,
 'Statement of Jayne Ann Lehmann', 13 February 2020, at [65–67]; Exhibit 4-4, 'Statement of
 Dr Rebecca Anne Kelly, 9 February 2020, at [124–137]; Transcript, Narelle Reynolds, Public
 Hearing 4, 24 February 2020, P-437 [24–29]; Transcript, Rachel Browne, Public Hearing 4,
 19 February 2020, P-83 [12] – P-84 [6]; Exhibit 4-11, 'Statement of Christine Regan',
 13 February 2020, at [44–48]; Transcript, Kim Creevey, Public hearing 4, 21 February 2020,
 P-322 [25]–P-324 [22]; Transcript, Sabrina Monaghan, Public Hearing 4, 24 February 2020,
 P-372–373; Exhibit 4-19, 'Statement of Jaqueline Terri Mills', 12 February 2020, at [28–33].

50 Exhibit 4-25, 'Statement of Jayne Ann Lehmann', 13 February 2020, at [105].

51 Exhibit 4-4, 'Statement of Dr Rebecca Anne Kelly', 9 February 2020, at [30], [38–39], [41].

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54 Transcript, Cecile Sullivan Elder, Public hearing 7, 12 October 2020, P-51 [26–28].

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57 Transcript, Breda Carty, Public hearing 29, 25 October 2022, P-110 [15–22].

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 hearing 7, 12 October 2020, P-68 [10–15]; Transcript, Catriona de Bruin, Public hearing 7,
 14 October 2020, P-248 [24–29]; Exhibit 7-06, 'Joint statement of Michelle O'Flynn and
 Nikki Parker', 23 September 2020, at [94].

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61 Transcript, Brittney Wilson, Public hearing 24, 6 June 2022, P-15 [6–9], [31–33].

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63 Exhibit 14-5, 'Statement of Karen Rogers', 5 May 2021, at [40].

- 64 Exhibit 20-0020.02, 'Statement of Greg', 16 November 2021, at [76]; Exhibit 20-0020.03, 'Statement of Michelle', 16 November 2021, at [61].
- 65 Exhibit 20-0064, 'Statement of Paul', 17 November 2021, at [56], [110].
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- 72 Exhibit 7-08, 'Statement of Cecile Elder', 28 September 2020, at [188]; Exhibit 7-07, 'Statement of Mary Sayers', 24 September 2020, at [79]; Exhibit 5-28, 'Statement of Mary Sayers', 24 September 2020, at [143].
- 73 Exhibit 7-08, 'Statement of Cecile Elder', 28 September 2020, at [45].
- 74 Exhibit 2-10, 'Statement of Deborah Pearl Wilson', 31 October 2019, p 4; Timothy Chan, Submission, 2 February 2021.
- 75 Exhibit 7-06, 'Joint statement of Michelle O'Flynn and Nikki Parker', 23 September 2020, at [63].
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- 77 Exhibit 2-12, 'Statement of Witness AAC', 2 November 2019, at [58–60].
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4. Health care and treatment

Key points

- People with disability have a right to equitable access to health care and treatment. However, there is a huge gap between the health outcomes experienced by people with disability and those experienced by the rest of the community.
- The evidence before the Royal Commission demonstrates that people with cognitive disability are subject to systemic neglect in the Australian health system.
- There are many barriers preventing people with all types of disability from enjoying the highest attainable standard of health without discrimination.
- We heard that the health system is complex and fragmented. Health services are not designed for people with disability and health workers do not have sufficient disability knowledge and skills. Negative attitudes can cloud decisions.
- Too often, people with disability have received poor care, the wrong care or no care. This is leading to poor health outcomes as well as trauma and distress. Health professionals have also failed to recognise and respond appropriately when people with disability are experiencing violence, abuse, neglect and exploitation.
- First Nations people with disability and other disadvantaged groups are more likely to receive poor health care or to have violence, abuse, neglect and exploitation experienced by them go unrecognised. Consequently, they experience even worse health outcomes than other groups with disability.
- To change this, we must build the capability of the health workforce to understand and respond to the different needs of people with disability.
- We must embed the right to equitable access to health services in the policy backbone of the health system – its national standards – and take a person-centred approach to the provision of care. We must ensure the health system is prepared to engage in preventive health care to reduce the higher risk of mortality for people with disability.
- Finally, we must change the structure of the system to support – not discourage – integrated care.

4.1. Introduction

Quality health care is an essential service, an enabler of human rights and a human right in itself. The *Convention on the Rights of Persons with Disabilities (CRPD)* expands on the universal right to health and recognises people with disability have the right to ‘the enjoyment of the highest attainable standard of health without discrimination on the basis of disability’.¹ Among other things, article 25 of the *CRPD* means that health professionals must provide care of the same quality to people with disability as to other people, including on the basis of free and informed consent.² This chapter considers whether Australia has implemented its obligations under the *CRPD* having regard to the disparities in health outcomes between people with disability and the rest of the community.

The chapter also discusses barriers to the right to health that the Royal Commission has identified. These barriers are extensive and can have significant, even fatal, consequences for people with disability. Professor Stephen Leeder AO, Emeritus Professor of Public Health and Community Medicine at the University of Sydney, said:

people suffering the consequences of violence and abuse often seek care in hospital. The effects of abuse or neglect are often expressed as health problems. It is also sadly the case that breaches in the health system can also cause these problems, as seen especially in the disrupted care of older patients or patients of any age with all levels of disability. Medicare was designed to remove financial barriers to essential care for all, but there are important non-financial barriers, such as culture and stigma, that can often be overriding factors in preventing some people from receiving the care that they need.³

This chapter will discuss three fundamental areas of reform that are required to provide access to quality health care for people with disability:

- Health professionals – Quality health care requires good communication and a relationship of trust, confidence and respect between a person with disability and the medical practitioners who provide them with care and treatment.
- Person-centred care – An individual’s needs and preferences should form the foundations for their care and treatment.⁴
- System coordination – The Australian health system is complex, and people with disability should be supported to navigate these systems to access quality health care.

Key areas of evidence

The Royal Commission held public hearings to examine the experiences of people with disability in the Australian health system. The first was Public hearing 4, ‘Health care and services for people with cognitive disability’.

Much of the evidence presented at Public hearing 4 concerned the experiences of people with intellectual disability and autistic people, included in the broader category of 'cognitive disability'. Cognitive disability arises from the interaction between a person with cognitive impairment and the attitudinal and environmental barriers hindering their full and effective participation in society on an equal basis with others.

Cognitive impairment is an umbrella term used to encompass actual or perceived differences in cognition. These include concentration; processing, remembering or communicating information; learning; awareness; and/or decision-making. People with cognitive disability may include, but are not limited to, people with intellectual disability, learning disability, dementia, or acquired brain injuries, and some people with autism.

We appreciate the limitations of categorising people with disability into particular cohorts based on their 'primary disability' type. Individual people's experiences vary and are influenced not only by the nature of their impairment but by multiple other factors that impact their health and wellbeing. Factors include gender, cultural background and identity, level of support and where people live. However, we know that people with all disability types face barriers to health care. This has been addressed in many other public hearings, submissions and private sessions. We expect that reforming the health system to address barriers to health care for people with cognitive disability will mean a more inclusive health system for all people with disability.

The Royal Commission began its health-related hearings with a focus on people with cognitive disability because of the serious health disparities faced by this group. The purpose of Public hearing 4 was to examine the health care and services provided to people with cognitive disability in Australia and to investigate whether this group of people is subject to systemic neglect by the health system. The hearing also examined why people with intellectual disability have a higher mortality rate compared to the general population, with death rates reported to be two to four times higher and life expectancy two decades shorter.⁵ Professor Julian Trollor, Chair of Intellectual Disability Mental Health at the University of New South Wales, said that people with intellectual disability and autistic people are overrepresented in terms of mental and physical health co-morbidities. These include sensory abnormalities, epilepsy, problematic feeding behaviours, respiratory and gastrointestinal diseases, mobility restrictions, frailty and premature ageing.⁶

Public hearing 6 concerned 'psychotropic medication, behaviour support and behaviours of concern'. Commissioners heard about barriers to health care faced by people with cognitive disability that lead to the over-prescribing and misuse of psychotropic medication.

Following Public hearing 4, the Royal Commission indicated it would investigate whether the training and education for health professionals could result in better quality health care and outcomes for people with cognitive disability.⁷ The education and training of health professionals was also considered in Public hearing 6.⁸ In Public hearing 10, 'Education and training of health professionals in relation to people with cognitive disability', Commissioners considered education and training in medicine, nursing, dentistry, pharmacy, speech pathology, psychology and allied health professions.

Other public hearings also discussed health care, including Public hearings 5, ‘Experiences of people with disability during the ongoing COVID-19 Pandemic’ and 12, ‘The experiences of people with disability, in the context of the Australian Government’s approach to the COVID-19 vaccine rollout’. The Royal Commission found:

- during the early stages of the COVID-19 pandemic, the Australian Government made no significant effort to consult with people with disability or their representative organisations⁹
- the Australian Government Department of Health made a decision to deprioritise the vaccination of people in disability residential settings¹⁰ but failed to make this public.¹¹

In Public hearing 11, ‘The experiences of people with cognitive disability in the criminal justice system’, and Public hearing 16, ‘First Nations children with disability in out-of-home care’, we heard about the need for culturally appropriate diagnostic assessment and health services for First Nations children with disability.¹²

In Public hearing 17, ‘The experience of women and girls with disability with a particular focus on family, domestic and sexual violence’, the Royal Commission heard from women with disability about the life long health consequences of violence, and the barriers to accessing health care and support for women and girls with disability who experienced violence.¹³ The Royal Commission also heard about sexual and reproductive rights of women and girls with disability.¹⁴

In Public hearing 29, ‘The experience of violence against, abuse, neglect and exploitation of people with disability from culturally and linguistically diverse communities’, witnesses described specific cultural and language barriers to health care faced by groups including the deaf community.¹⁵

In Public hearing 30, ‘Guardianship, substituted and supported decision-making’, the Royal Commission heard about barriers to accessing health care and the powers of guardians to make substitute decisions about health care and treatments for people with disability who are subject to guardianship orders.

From what the Royal Commission heard in all our public hearings it is apparent that work needs to be done before people with disability will be able to access the health system on an equal basis to those without disability. In addition to the public hearings, the health of people with disability and access to health care has been a key theme in submissions and private sessions.

4.2. Right to quality health care

Convention on the Rights of Persons with Disabilities

Article 25 of the *CRPD* recognises people with disability have the right to ‘the enjoyment of the highest attainable standard of health without discrimination on the basis of disability’.¹⁶ Article 25 also recognises the intersectional experiences of people with disability in accessing health

care, expressly requiring governments to ‘take all appropriate measures to ensure access for persons with disabilities to health services that are gender-sensitive, including health-related rehabilitation’.¹⁷

Article 25 includes six specific obligations. States Parties must:

- a) Provide persons with disabilities with the same range, quality and standard of free or affordable health care and programmes as provided to other persons, including in the area of sexual and reproductive health and population-based public health programs;
- b) Provide those health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimize and prevent further disabilities, including among children and older persons;
- c) Provide these health services as close as possible to people’s own communities, including in rural areas;
- d) Require health professionals to provide care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent by, inter alia, raising awareness of the human rights, dignity, autonomy and needs of persons with disabilities through training and promulgation of ethical standards for public and private health care;
- e) Prohibit discrimination against persons with disabilities in provision of health insurance, and life insurance where such insurance is permitted by national law, which shall be provided in a fair and reasonable manner;
- f) Prevent discriminatory denial of health care or health services or food and fluids on the basis of disability.¹⁸

In addition, under article 26 of the *CRPD*:

States Parties shall take effective and appropriate measures, including through peer support, to enable persons with disabilities to attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life. To that end, States Parties shall organize, strengthen and extend comprehensive habilitation and rehabilitation services and programmes, particularly in the areas of health, employment, education and social services.¹⁹

The specific rights and needs of women and girls with disabilities in the area of sexual and reproductive health are reflected in a number of provisions in the *CRPD*. Article 25 of the *CRPD* expressly refers to sexual and reproductive health. Article 6(1) provides:

States Parties recognize that women and girls with disabilities are subject to multiple discrimination, and in this regard shall take measures to ensure the full and equal enjoyment by them of all human rights and fundamental freedoms.²⁰

On 29 August 2018, the Committee on the Rights of Persons with Disabilities (CRPD Committee) and the Committee on the Elimination of Discrimination against Women issued a joint statement calling on States to ‘adopt effective measures to enable women, including women with disabilities, to make autonomous decisions about their sexual and reproductive health’.²¹ The joint statement emphasised that it is:

critical that these decisions are made freely and that all women, including women with disabilities, are protected against forced abortion, contraception or sterilization against their will or without their informed consent.²²

Realising the right to health

In Public hearing 4, we examined the healthcare experiences of people with cognitive disability and expert research on their health outcomes. This evidence demonstrates people with disability do not enjoy the right to health recognised by the *CRPD*. It also suggests there are systemic problems in providing health services to people with cognitive disability.

Professor Julian Trollor, Chair of Intellectual Disability Mental Health at the University of New South Wales, told the Royal Commission:

People with intellectual disability and autistic people experience a mismatch between their health care needs and the health care services they currently receive. Gaps are systemic and pervasive in nature and span inadequate engagement in preventative health care services, missed diagnosis and poor end-of-life care and disease and risk management, and non-evidence based prescribing practices. Poor health trajectories and increased mortality among Australians with intellectual disability and autistic Australians, particularly from causes that are potentially avoidable or amenable to intervention emphasise core failures within our current health care system to meet the needs of these vulnerable populations. Urgent action on these issues is required in order that Australia meet its obligations under the UNCRPD.²³

The CRPD Committee’s *Concluding observations on the combined second and third periodic reports of Australia* raise concerns aligning with Professor Trollor’s evidence:

The Committee is concerned about the fact that, compared to the general population, persons with disabilities, in particular persons with disabilities living in remote areas, Aboriginal and Torres Strait Islander persons with disabilities, persons with intellectual or psychosocial disabilities, persons with disabilities living in institutions and children and women with disabilities, are in significantly poorer health and have less access to information and to adequate, affordable and accessible health services and equipment.²⁴

The CRPD Committee recommended that the Australian Government ensures:

(a) All persons with disabilities, in particular persons with disabilities living in remote areas, Aboriginal and Torres Strait Islander persons with disabilities, persons with intellectual or psychosocial disabilities, persons with disabilities living in institutions and women and children with disabilities, have access to information on an equal basis with others and to affordable, accessible, quality and culturally sensitive medical equipment and health services, including sexual, reproductive and mental health services;

(b) All health-care services are based on a non-discriminatory, human rights model of disability and that any medical treatment is provided with the free and informed consent of the person concerned prior to any medical treatment;

(c) Health-care practitioners receive training on the human rights model of disability to enhance their capacity to provide accessible, quality health care to persons with disabilities.²⁵

While Commissioners acknowledged that practices are changing in some parts of the health system, their overall conclusion following Public hearing 4 was:

a great deal more needs to be done if people with cognitive disability are to receive in practice, as well as in theory, the right recognised in article 25 of the *CRPD*, namely, the right to enjoyment of the highest attainable standard of care without discrimination on the basis of disability.²⁶

Commissioners found ‘people with cognitive disability have been and continue to be subject to systemic neglect in the Australian health system’.²⁷

In a report prepared for the Royal Commission, *The United Nations Convention on the Rights of Persons with Disabilities: An Assessment of Australia’s Level of Compliance*, Emeritus Professor Ron McCallum AO considered articles 25 and 26. After review of the CRPD Committee’s 2019 *Concluding observations*, he said:

it is clear that Australia is complying with articles 25 and 26 of the *CRPD*. The NDIS is a big step forward supporting the wellbeing of persons with disabilities. However, as the Australian Human Rights Commission noted in its recommendations, there are still significant problems to be overcome. They concern the provision of health services to remote areas; ensuring that First Nations peoples can access adequate health care; improving mental health services and facilities; providing medical services in First Nations Languages and with sign interpreters; and training medical staff about the needs of persons with disabilities.²⁸

Proposed Disability Rights Act

The human right to the enjoyment of the highest attainable standard of health in international law has not been implemented into Australia law. The *Human Rights Act 2019* (Qld) is the only Australian law that expressly recognises the right to health as a human right.

In Volume 4, *Realising the human rights of people with disability*, we recommend the Australian Government legislate a right of people with disability to equitable access to health services as part of an Australian Disability Rights Act.

This chapter makes recommendations to support equitable access to health care and treatment for people with disability that complement that proposed statutory right. This includes embedding equal access in national standards and targeting known barriers through education, investment and coordination.

4.3. Health system

Delivery context

Medicare is Australia's universal health insurance scheme. It includes free or subsidised health care in public hospitals and provides government-funded rebates or benefits to patients, including those with disability, for healthcare services provided in the community.²⁹

In Australia, the health system comprises health promotion, primary, secondary and tertiary care, and rehabilitation.³⁰ Financial and managerial responsibility for this system is shared by the Australian Government and state and territory governments.³¹ Their respective roles and responsibilities are set out in the National Health Reform Agreement (NHRA).³²

Primary care is generally a person's first contact with the health system.³³ In the Australian context it usually refers to general practice, as well as community-based nursing and allied health care. Primary health networks connect general practitioners and other health professionals to each other, and provide incentives to implement national programs at a local level.³⁴

Under the Medicare Benefits Schedule, the Australian Government pays a Medicare benefit to patients to subsidise fees they have been charged by general practitioners, specialists and some allied health services.³⁵ The Australian Government also provides grant funding through the Indigenous Australians' Health Programme to Aboriginal Community Controlled Health Services and other services.³⁶

Secondary and tertiary care is provided by hospitals and private medical specialists.³⁷ Public hospitals are managed by states and territories and the system varies between jurisdictions. Funding responsibility for public hospitals is shared by the Australian Government and state and territory governments.³⁸ The Australian Government contribution is calculated by the

Independent Health and Aged Care Pricing Authority, in the form of a National Efficient Price.³⁹ Local hospital networks provide hospital and health services to communities within fixed geographical areas.⁴⁰

Rehabilitation services are provided in various settings by specialist doctors, nurses and allied health professionals.⁴¹

The Australian Government and state and territory governments also share responsibility for population health. This includes prevention, protection and health promotion (such as anti-smoking campaigns).⁴²

There are two pathways to access dental care in Australia: the public system or the private system.⁴³ In the public system, the Australian Government and state and territory governments share responsibility for dental services. The Australian Government contributes funds for public dental services delivered by the states and territories.⁴⁴ Patients access private dental services on a fee-for-service basis, regardless of jurisdiction.⁴⁵

The Australian Government regulates private health insurance. Individuals may purchase private health insurance cover for hospital services and/or other health services that are not publicly funded (which can include services like dental, ambulance and physiotherapy).⁴⁶

Section 4.5 describes the national framework for regulating health practitioners, including accreditation of programs of study.

Health services may also be provided in specific settings such as aged care, corrective services and justice, and education settings. Of relevance to this chapter, they may also be provided in disability settings.

Australia's health policy context

The health policy context has continued to evolve over the course of our inquiry. A number of recent developments align with or have been influenced by evidence we have heard, and by our findings and recommendations. We also discuss these in Volume 12, *Beyond the Royal Commission*.

Australia's Disability Strategy 2021–2031

Australia's Disability Strategy 2021–2031 (ADS) identifies health and wellbeing as a key outcome area.⁴⁷ The policy priorities to achieve this outcome align with key health care access issues examined in our inquiry. This includes the need for improved workforce capability, prevention and early intervention, mental health care, and disaster preparedness and public emergency responses.⁴⁸ Volume 5, *Governing for inclusion*, considers the development and implementation of the ADS.

National Roadmap for Improving the Health of People with Intellectual Disability

The Australian Government released the National Roadmap for Improving the Health of People with Intellectual Disability (the National Roadmap) in August 2021, more than one year after Public hearing 4. The National Roadmap sets out a vision to reform the health system over 10 years to meet the healthcare needs of people with intellectual disability.⁴⁹ It forms part of Australia's Primary Health Care 10 Year Plan 2022–2032.⁵⁰ It is an associated plan to the ADS, and supports health and wellbeing outcomes under the ADS.⁵¹ The Australian Government has committed to consider the findings and recommendations of the Royal Commission in implementing the National Roadmap.⁵²

The National Roadmap identifies 56 actions to improve the health of people with intellectual disability under nine key elements:⁵³

- improved support for people with intellectual disability and their families and carers
- developing models of care
- better use of existing Medicare Benefits Schedule funding items
- continuity of care, and better care coordination and integration within the health system
- better coordination with other sectors
- better support for healthcare professionals to provide better care for people with intellectual disability
- improving oral health for people with intellectual disability
- research, data and measurement to support continuing improvement
- emergency preparedness and response.

Commissioners welcomed the inclusion of initiatives to address the systemic neglect of people with disability in the health system as part of the National Roadmap. However, they noted the Australian Government would need to 'provide the resources to ensure the robust implementation of the initiatives that have been developed'.⁵⁴

Commissioners said:

These initiatives must be implemented nationally; data must be gathered systematically and research undertaken to evaluate their success in improving the health of people with cognitive disability; steps must be taken to change entrenched negative attitudes and assumptions made by many health professionals and institutions about people with cognitive disability; health professionals must acquire the specialised skills required to equip them to care for and support people with cognitive disability; and active steps must be taken to address the particular healthcare needs of people with autism.⁵⁵

As of January 2023, the Australian Government had committed a total of \$43.3 million to fund the following National Roadmap priorities:⁵⁶

- the Primary Care Enhancement Program for people with intellectual disability
- increasing the uptake of annual health assessments and comprehensive health planning for people with intellectual disability
- curriculum development in intellectual disability health
- a National Centre of Excellence in Intellectual Disability Health.

As of March 2023, the Australian Government was yet to announce how it will resource the remainder of the National Roadmap work program and its evaluation.

The Australian Government Department of Health and Aged Care (the Department) has set up a Roadmap Implementation Governance Group (RIGG) to oversee implementation of the National Roadmap.⁵⁷ The RIGG is chaired by the Department and includes people with disability and representatives of disability organisations, a disability service provider, health profession colleges and associations, a primary health network, Australian Government agencies, and state and territory agencies.⁵⁸ The Department has also established an Intellectual Disability Focus Group to ensure appropriate engagement with people with intellectual disability across all projects under the National Roadmap.⁵⁹

The RIGG has agreed to provide an annual public report on progress towards achieving outcomes under the National Roadmap.⁶⁰ As of March 2023, we have not seen a separate consolidated annual report. However, the Department's website has details of progress on initial National Roadmap measures.⁶¹

Australia's Primary Health Care 10 Year Plan 2022–2032

In March 2022 the Australian Government released Australia's Primary Health Care 10 Year Plan 2022–2032. The plan builds on major shifts in the health system underway in response to this Royal Commission, other inquiries and the COVID-19 pandemic. It has a specific action area to 'improve access to appropriate care for people at risk of poorer health outcomes', which includes people with disability.⁶² It includes a commitment to respond to our *Final report* with further primary healthcare reforms.⁶³

Long-term health reform

All Australia's health ministers endorsed a National Health Reform Agreement (NHRA) long-term reforms roadmap at the Health Ministers Meeting on 17 September 2021 (NHRA Roadmap). The NHRA Roadmap is aimed at removing systemic barriers to health care.⁶⁴

The NHRA Roadmap is intended to benefit everyone. However, we note the reforms will help to address systemic barriers to health care for people with disability. This includes a specific reform stream to improve interfaces between health, disability and aged care systems and measure

system interface performance.⁶⁵ Timeframes for actions under the NHRA Roadmap extend from 2021–22 to 2024–25.⁶⁶

While these reform directions look promising, the Royal Commission has insufficient information to gauge progress. Governments are due to complete a mid-term review by December 2023 of the addendum to the NHRA which amends the NHRA for the period of 1 July 2020 to 30 June 2025.⁶⁷ This review should consider impacts on people with disability and our recommendation in Volume 5 to align national agreements with the ADS and the proposed National Disability Agreement.

National Autism Strategy and National Roadmap to Improve the Health and Mental Health of Autistic People

The 2022–23 October Australian Government Budget included the Better Support for People with Disability package. This includes \$5.3 million to support the development of a National Autism Strategy led by the Australian Government Department of Social Services.⁶⁸ The Australian Government Department of Health and Aged Care is leading the development of a national roadmap to target health and mental health outcomes for autistic people.⁶⁹

International context

In December 2022 the World Health Organization (WHO) released its *Global report on health equity for persons with disabilities*. It examined health inequities experienced by people with disability and the social determinants, risk factors and health system barriers that may contribute to those inequities. This includes many of the barriers identified in evidence presented to us, such as health workforce capability,⁷⁰ unconscious bias,⁷¹ data and information limitations,⁷² service gaps,⁷³ service fragmentation,⁷⁴ accessibility of services and information,⁷⁵ and involuntary treatment.⁷⁶

The WHO observed:

Substantial progress has been made in many countries; nonetheless, the world is still far from realizing the right to the highest attainable standard of health for persons with disabilities. This report shows that persons with disabilities continue to experience a wide range of health inequities. Contributing factors to these inequities remain unchanged during the past decade, and many persons with disabilities continue to die prematurely, have poorer health, and experience more functioning limitations as a result. The COVID-19 pandemic revealed the disadvantaged position of persons with disabilities within and beyond the health sector, and the need for urgent action.⁷⁷

Consistent with Commissioners' recommendations following Public hearing 5 and Public hearing 12,⁷⁸ the WHO identified key lessons from the global COVID-19 pandemic response. They include the need for: participation of people with disability in decision-making; accessible public health interventions and information; building the disability capability of health professionals; developing person-centred, rights-based health services and support in the community;

accessible digital health services; and collecting and disaggregating data by disability to monitor impacts.⁷⁹ In addition, the WHO called for a broader reshaping of the health sector to ensure greater inclusion and equity, reduce risks and build resilience to respond to future health emergencies.⁸⁰

To advance health equity, the WHO outlined 40 targeted actions to integrate health services, take a multisectoral approach beyond the health system, and to empower people with disability and their communities.⁸¹ If implemented by governments in Australia, these actions could significantly improve health outcomes for people with disability.

Ableism and the medical model of disability

Our vision for an inclusive Australia describes how ableist attitudes towards disability are deeply connected to cultural beliefs and practices that see disability as a deficit or departure from a 'norm' or as a health or medical problem requiring treatment or cure. As discussed in Section 4.5, this mindset is commonly referred to as the 'medical model' of disability, and perceives people with disability as vulnerable, in need of protection, or different.⁸²

In Public hearing 4, we heard how ableism is a barrier and how ableist attitudes and practices adversely impact the quality of health care received by people with cognitive disability. Health professionals consciously or unconsciously often make negative and false assumptions about the quality of life of people with disability.⁸³ Doctors may presume that parents should or will want to terminate fetuses with disability and may unfairly judge parents who choose not to do so.⁸⁴

Negative attitudes can also lead to 'diagnostic overshadowing'. Diagnostic overshadowing occurs when a person's symptoms or behaviours are wrongly attributed to their impairment rather than to an unrelated health problem or condition. This may lead to delayed or mistaken diagnosis of serious medical conditions.⁸⁵ Professor Trollor described diagnostic overshadowing as a 'major problem for people accessing services' and said:

when frontline health services hear from a person with disability, often they may see or hear about the disability first and may prioritise that issue, rather than listening carefully to the range of symptoms someone may present with.⁸⁶

Diagnostic overshadowing may be a consequence of insufficient education or training concerning cognitive disability. It may also reflect an underlying culture, including ableism, within the health system in relation to people with disability. Ableism can also be a driver of the reluctance of some psychiatrists to treat people with intellectual disability and of the over-prescription of psychotropic medication in response to what are described as 'behaviours of concern'.⁸⁷

In Public hearing 29, representatives of the Deaf community told us how the 'medical deficit model' adversely impacts the life course of a deaf child. They emphasised that when a deaf child is diagnosed, their parents should receive unbiased information and supports.⁸⁸

However, witnesses described the use of negative language by medical professionals when disclosing newborn screening test results, and the sharing of biased information with parents.⁸⁹

The CEO of Deaf Australia, Jen Blyth, told us deafness is presented as a problem that needs to be fixed.⁹⁰ We also heard that the information provided to parents is narrow, focusing on a medical deficit pathway. Holistic messaging, which includes references to Deaf culture, Auslan and the Deaf community, is not presented to parents.⁹¹ Auslan is usually only suggested as a last resort when the auditory/oral deficit approach has been unsuccessful.⁹² We heard similar accounts from families and supporters of people with a range of other disabilities including cognitive disability, such as Down syndrome,⁹³ and physical impairments, such as spinal cord injury.⁹⁴

Dr Rebecca Kelly is the mother of then eight-year-old Ryan, who lives with Down syndrome and has very complex medical needs.⁹⁵ In Public hearing 4, she described how important it was to her to have a positive experience after giving birth to Ryan. A health practitioner took the time to sit and talk when Dr Kelly learned of her son's Down syndrome.⁹⁶

In Public hearing 4, other witnesses with cognitive disability and their families also described positive experiences in the health system. Many health professionals are already well aware of the challenges in providing high-quality care to people with cognitive disability and are prepared to take the measures necessary to address these challenges. Some institutions have also introduced programs designed to provide better health care and outcomes for people with disability.⁹⁷

Unintended loss of specialised knowledge

While the move away from the medical model of disability is welcome, it has had unintended consequences for the provision of health care to people with disability. One of the consequences was an assumption the general or mainstream health system would accommodate people with disability living in the community. A further consequence was the loss of specialist skills to support the particular health requirements of some people with disability. Dr Catherine Franklin, a specialist psychiatrist working with patients with intellectual disability, gave evidence at Public hearing 6. She said:

In my view, the de-institutionalisation movement, occurring at a time when there was increased focus on human rights and normalisation theory, effectively distanced people with intellectual disability and the medical profession. People with intellectual disability were seen as requiring social support, not medical care.⁹⁸

She described how, following de-institutionalisation, 'there seems to be really a lack of feeling of responsibility for people with intellectual disability as a specialist group requiring additional, if anything, care rather than less care'.⁹⁹

In Public hearing 10, Professor Trollor observed that separating the disability and health sectors resulted in a de-skilling of the medical workforce. This was accompanied by less emphasis on training, exposure to, and awareness of, the needs of people with disability.¹⁰⁰ Professor Trollor noted that the previous National Disability Strategy is clear that the health sector is responsible for meeting the health needs of people with disability. However, he said it was ‘very difficult for a document like that to mobilise a response in another compartment that views itself separately’.¹⁰¹

4.4. Barriers to equal access and impact on health outcomes

The evidence from numerous people with cognitive disability and their families, carers and support persons, and from disability advocates, was powerful and consistent. It validates the existence of formidable barriers to quality health care in Australia for people with cognitive disability. These barriers arise because of attitudes and structural arrangements in the health workforce, lack of access to person-centred care, and systemic issues, each of which is described in this section. We explore the barriers in detail in the following three sections, with accompanying recommendations for change.

In Public hearing 4 we were told of the significant gap in health outcomes experienced by people with cognitive disability, relative to the general population and their particular healthcare needs.¹⁰² Professor Trollor outlined the research done recently by his team, which has identified, among other things, a high rate of avoidable deaths for people with intellectual disability. In a six and a half year period in New South Wales, ‘38 per cent of deaths of people with intellectual disability were found to be from potentially avoidable causes - a figure more than double that of the general population’.¹⁰³ He also drew attention to research showing that the median age of death in New South Wales for an adult cohort with intellectual disability is 27 years lower than that of the general population (54 years compared with 81 years).¹⁰⁴

During Public hearing 4 and Public hearing 6, the Royal Commission heard from a number of witnesses about barriers to quality mental health care and treatment faced by people with cognitive disability.¹⁰⁵ There was evidence about high rates of mental health conditions among people with cognitive disability. Professor Trollor stated:

Best estimates suggest that for common disorders such as schizophrenia, affective and anxiety disorders and dementias, prevalence in people with intellectual disability is 2 to 3 times that of the general population ... Very high rates of mental ill health have also been reported in people on the autism spectrum. Depression and anxiety disorders are the most common conditions experienced.¹⁰⁶

He attributed the gap in health outcomes to a combination of poor preventive health care, missed diagnoses and lack of evidence-based disease management.¹⁰⁷

Data from the Australian Institute of Health and Welfare (AIHW) in 2018 indicated that 7.6 per cent of people with disability aged 64 and under who needed to see a general practitioner in the past 12 months delayed or did not go because of cost.¹⁰⁸ This rose to 28 per cent for those who needed to see a dental professional.¹⁰⁹ Half of the people aged five to 64 years with disability who needed healthcare assistance received only informal assistance.¹¹⁰

People with disability aged 15 to 64 are less likely (47 per cent) to have some form of private health insurance than those without disability (59 per cent).¹¹¹ This has an impact on access to health care. In 2020–21, the time on public hospital elective surgery waiting lists was significantly longer for public patients (50 per cent admitted within 51 days) than for private health insurance patients (50 per cent admitted within 23 days).¹¹²

Some people with disability face discrimination from healthcare staff. This especially affects people with severe disability or in remote areas.¹¹³ The AIHW reported that 25 per cent of people with disability who experienced discrimination from healthcare staff subsequently avoided health facilities.¹¹⁴

There are particular failures of the health system to provide adequate care for First Nations people with cognitive disability. In Public hearing 4, Dr Scott Avery, Senior Lecturer and Research and Policy Director, School of Social Sciences, Western Sydney University, described the concept of ‘intersectionality’, noting that people who belong to two or more marginalised groups are ‘double-disadvantaged’¹¹⁵ The Royal Commission defines ‘intersectionality’ as a way of understanding a person with disability’s unique experience of multi-layered and intersecting discrimination and disadvantage based on their personal characteristics. These characteristics can include age, sex, gender, gender identity, sexual orientation, intersex status, ethnic origin or race, including the particular situation of Aboriginal and Torres Strait Islander people with disability and culturally and linguistically diverse people with disability. Intersectionality is discussed in further detail in Volume 3, *Nature and extent of violence, abuse, neglect and exploitation*.

Dr Avery described how negative stereotypes of First Nations people (for example, around drinking) undermine robust diagnostic procedures. He noted First Nations people appear to be:

particularly susceptible to this intersectional form of institutionalised discrimination at the first point of contact within the health system, such as when being treated by an ambulance or at an emergency ward.¹¹⁶

Dr Avery said the healthcare system is characterised by a ‘culture of avoidance’ where ‘people in positions of authority within the system have refused to accept that health inequalities for people with disability even exist’.¹¹⁷ In research commissioned by the Royal Commission, Dr Avery considered the concept of ‘structural violence’. This is ‘harm done to individuals or groups through the normalisation of social inequalities in political-economic organization’.¹¹⁸ He noted:

There is a direct connection between structural violence and exposure to personal violence. The structural disempowerment of being ‘out of sight, out of mind’ manoeuvres people into socially isolating situations where they become vulnerable to personal incidents of violence.¹¹⁹

Ms Narelle Reynolds is a Wiradjuri woman who has worked as an enrolled nurse and coordinated health services for First Nations families. She described the challenges navigating the health system as a First Nations person and as an advocate for her sons. She told us that ‘being Aboriginal on top of being a mother of children with intellectual disability is a double whammy’.¹²⁰

Data from the Australian Bureau of Statistics similarly suggests First Nations people with disability experience additional challenges in managing their health and accessing health services.¹²¹ In 2018–19, only one in eight (12 per cent) of First Nations people aged 15 to 64 with a ‘profound or severe disability’ reported excellent or very good self-assessed health. This was around one-fifth the rate reported by First Nations people with no disability (61 per cent).¹²² First Nations people aged 15 to 64 with ‘profound or severe disability’ were almost twice as likely to have faced barriers accessing health services (65 per cent) as those with no disability (34 per cent).¹²³

Workforce

Attitudes, assumptions and culture

Assumptions and attitudes can influence the treatment of people with cognitive disability. Many witnesses gave examples of health professionals’ negative assumptions and attitudes about people with cognitive disability.

We heard that people with cognitive disability experience barriers to treatment and are likely to have symptoms attributed to their disability, even when they are unrelated. People with cognitive disability face unhelpful assumptions from some medical professionals about their ability to communicate or make decisions about their own treatment. We heard that they are also likely to have treatable pain ignored or overlooked and wait longer for a diagnosis than people without disability:

if a person with disability suffers from something for long enough, momentum can be lost in terms of finding solutions. People become complacent and see health issues as just something that’s ‘part’ of the person or disability.¹²⁴

Ms Rachel Browne described the way negative attitudes led to inaction at a critical time when she brought her son Finlay to the local hospital emergency department to treat severe abdominal pain. Ms Browne said ‘the triage nurse, when I looked up, rolled her eyes. And I thought, “That’s it. We’re not going to get the help we need.”’¹²⁵

We heard about the great distress that can be caused when the death certificate of a person with cognitive disability inappropriately attributes the cause of death to the disability, rather than the underlying medical condition.¹²⁶ As Professor Trollor said, this practice makes no sense and it is very important to record and analyse accurate data about the deaths of people with cognitive disability and their causes.¹²⁷ Volume 11, *Independent oversight and complaint mechanisms*, elaborates on the use of death review processes.

Research we commissioned from the Social Policy Research Centre included a review of literature on interventions to promote positive attitudes towards people with disability in the area of health and wellbeing.¹²⁸ Two reports were identified that drew attention to intersectionality, discrimination and lack of training about LGBTIQ+ issues among health workers,¹²⁹ and for First Nations people.¹³⁰

In their *Report of Public hearing 4: Health care and services for people with cognitive disability*, Commissioners concluded:

Negative attitudes and assumptions are by no means universal within the health system. But they are sufficiently widespread to influence the nature and quality of care received by people with cognitive disability.¹³¹

Diagnostic overshadowing leads to symptoms or behaviour being attributed to a person's cognitive disability, rather than to underlying health conditions unrelated to the particular disability. The result can be a delayed diagnosis or a failure to diagnose a treatable condition.

Negative attitudes towards disability can also result in health professionals failing to recognise and respond when people with disability are experiencing violence, abuse, neglect and exploitation.¹³² Volume 11 addresses the multiple barriers to reporting of violence, abuse, neglect and exploitation of people with disability.

Restrictive practices

Public hearing 6 examined the ways people with cognitive disability are treated when they display what are commonly referred to as 'behaviours of concern'.

The hearing examined the regulatory framework for administration of psychotropic drugs as a 'restrictive practice' known as 'chemical restraint'. Witnesses spoke about the use of medication reviews to monitor for adverse side effects and provide an opportunity to initiate deprescribing of psychotropic medications.¹³³ Commissioners observed that greater skills and expertise are needed among health and disability professionals to:¹³⁴

- address attitudes, assumptions or beliefs that behaviours of concern are the fault of the person with cognitive disability
- recognise and address underlying causes of behaviours of concern
- enhance methods of communication to ensure that informed consent to the use of psychotropic medication is given wherever possible
- recognise and implement positive behaviour support as an alternative to psychotropic medication.

Chapter 5, 'Restrictive practices', investigates the use of restrictive practices in detail. It is also addressed below in Section 4.5.

Education and training of health professionals

In Public hearing 4, a wide range of witnesses proposed further education and training for health professionals, primarily to ensure their decisions about diagnosis and treatment are not informed by preconceptions about people with cognitive disability.¹³⁵ Witnesses also said health professionals needed education and training to improve communication with people with cognitive disability and their parents, carers and support persons.¹³⁶ Several advocates and experts remarked on health professionals' limited exposure to people with cognitive disability in the course of their training and clinical work. This can result in limited understanding of cognitive disability and of practices likely to foster trust and understanding between doctor and patient.¹³⁷ Section 4.5 discusses this education and training in more detail, referencing Public hearing 10 and making recommendations.

Amiah*

Amiah is blind and uses braille.

She grew up in a refugee camp with no access to special education or technology.

Amiah told the Royal Commission she never felt like she had a disability because her father encouraged her to do everything her siblings did.

'My family and community were very supportive, and they have actively helped and assisted me to be independent ... This has made me very capable of living by myself and managing my needs.'

Amiah came to Australia in her late teens. Since then, she said, she has 'felt discriminated against'.

'The cultural differences and the isolation in school started to make my life stressful. I was more aware, conscious and anxious about being a blind person.'

Following school, Amiah started a relationship with a man who has vision impairment.

Amiah and her partner decided to start a family. Their GP referred them to an IVF clinic because 'there were issues having a baby naturally'.

'The consultations with the IVF clinic helped me make an informed decision. Several tests including genetic testing were done, and all tests came out good.'

Amiah was able to self-administer hormone injections by listening for the clicks the injection device would make. She said it would have been safer and easier if the instructions and markings on the device were in braille.

IVF was successful, but Amiah's joy was crushed by people's negative attitudes to her pregnancy.

People saw only a 'blind lady who is pregnant' instead of a person who wished to be a mother.

‘I have been discriminated against, judged and questioned by many people. I had to always say, “This is not an accidental baby.”’

She said health professionals were the worst.

They constantly questioned her capacity, asking if she was physically and mentally prepared to look after the baby.

One person demanded to know who was going to stay awake and take care of the baby at night.

‘I want to be that person, I wanted to be a mother.’

Another person told her she had ‘other options’ and could find someone else to look after the baby.

‘I wonder if they would ask the same of any parent who is in the same situation.’

Amiah’s baby was born a few weeks premature.

‘I was not able to hold the baby for 10 days, which was traumatising for me.’

Amiah’s partner overheard health professionals discussing whether Amiah would be able to care for the baby. Another asked him whether he or Amiah would cope. Amiah said people often treated them as if they were invisible, talking about their capacity in front of them.

‘As a blind person and a person with a disability, my whole life turns into a constant journey of proving self-capacity to everyone,’ Amiah said. ‘Everyone has a right to have a family and a baby.’

Amiah said that instead of feeling ‘harassed and constantly questioned and coming home being anxious about fear of losing [her] baby’, she would have liked practical support. For example, instructions for baby products, medications and supplies in braille would have been helpful.

Lack of access to person-centred care

Witnesses in Public hearing 4 consistently stressed the importance of a ‘person-centred approach’ in addressing the health needs of people with cognitive disability. A person-centred approach requires health professionals and institutions to support people to make informed decisions about their own care and treatment. It is critical for the person with cognitive disability – and their family and support persons – to have trust and confidence in their health professionals. Once trust and confidence are established, collaborative planning allowing people with cognitive disability to exercise choice and control over their health care becomes possible.¹³⁸

Lack of supported decision-making in health care

We heard there is a general presumption in the health system that people with all disability types lack the capacity to make decisions about their own health care.¹³⁹ A number of witnesses with disability and their support persons gave evidence about the importance of supported decision-making in health care. Mr Jack Kelly is a person with disability who works at the Council for Intellectual Disability. He said it is important for people with intellectual disability to be involved in decision-making because ‘we all should be treated as an equal and not as a dis-equal’.¹⁴⁰ The CEO of the Council for Intellectual Disability, Ms Justine O’Neill, observed how a person with intellectual disability might lose their decision-making rights informally or formally without support.¹⁴¹

Recommendations in this chapter seek to implement supported decision-making within the health system. They complement recommendations in Chapter 2 of this volume, ‘Supported decision-making’, to reform guardianship and administration legislation to better recognise and embed supported decision-making. La Trobe University identified challenges facing supported decision-making in the healthcare context.¹⁴² These include barriers such as ‘lack of time, competing clinical work, fragmented care services, inadequate professional collaboration and uncertainty in professional roles in relation to supported decision-making’.¹⁴³

The Victorian Government drew attention in a submission to legislation adopting the Australian Law Reform Commission’s national supported decision-making principles, including the *Medical Treatment Planning and Decisions Act 2016* (Vic) and the *Mental Health Act 2014* (Vic). The *Mental Health and Wellbeing Act 2022* (Vic), which was enacted following the Royal Commission into Victoria’s Mental Health System, also recognises the importance of supported decision-making.¹⁴⁴

Under the *Medical Treatment Planning and Decisions Act 2016* (Vic), a person can appoint a ‘medical support person’ to help them make, communicate and give effect to medical treatment decisions. When the person does not have decision-making capacity to make medical treatment decisions, their medical support person represents their interests. For example, the medical support person might explain the person’s previous treatment preferences to medical staff.¹⁴⁵ A medical support person does not have the authority to make a person’s medical treatment decisions unless they are also appointed as a ‘medical treatment decision maker’.¹⁴⁶

Victoria's new *Mental Health and Wellbeing Act 2022* includes the principle that:

persons receiving mental health and wellbeing services are to be supported to make decisions and to be involved in decisions about their assessment, treatment and recovery including when they are receiving compulsory treatment. The views and preferences of the person receiving mental health and wellbeing services are to be given priority.¹⁴⁷

The Victorian Government submitted that all jurisdictions should reform their legislation and legal frameworks on supported individual decision-making, including their medical treatment and mental health laws, to ensure a nationally consistent approach.¹⁴⁸

In Volume 4, we recommend the proposed legislative right to equitable access to health services under a new Australian Disability Rights Act include the presumption of legal capacity and provision for supported decision-making.

Legislation alone will not be sufficient to implement supported decision-making in health care. The La Trobe University research highlighted examples of health services failing to comply with legislation in their healthcare decisions.¹⁴⁹ It also highlighted low levels of legal knowledge by health professionals.¹⁵⁰

The researchers concluded there is a 'need for leadership and cultural change, as well as targeted training if supported decision-making is to be understood and practice changes successfully implemented in the healthcare context'.¹⁵¹

Distress and trauma

The Royal Commission received significant evidence about the trauma and distress people with cognitive disability can experience when they undergo health procedures or treatment.¹⁵² Ms Browne described the experiences of her son Finlay:

Over Finlay's 16 years he had multiple encounters and interactions with members of the health system; every poor encounter is remembered. This, in turn, creates a sense of unease and fear going into the next encounter; combine that with an environment that assaults your senses and scares you and on top of that, that you are also sick or in pain. Anyone's level of compliance is going to be sorely tested, but given the right skills and a true sense of compassion and a desire to help in the health system's staff, it is not unattainable.¹⁵³

Several witnesses gave evidence about the impact of the sensory environment on a person with cognitive disability. Dr Jacqueline Small, an expert witness in Public hearing 4, said presenting to an emergency department in particular is a 'stressful, anxiety-provoking situation' for anyone and can lead to 'increased challenging behaviours or distress for a person with intellectual disability'.¹⁵⁴

These stress-induced ‘challenging’ behaviours can be extremely detrimental to good health care – for example, if treatment has to be postponed or abandoned.¹⁵⁵ Repeated distressing experiences can cause people with cognitive disability and their families to lose trust in the health system and fear further interactions.¹⁵⁶ A traumatic experience in the health system can have implications for every aspect of life for people with cognitive disability. Dr Kelly said the trauma of her son Ryan’s hospitalisation contributed to a significant escalation in his anxiety and regression in his behaviour over a whole term at school.¹⁵⁷

The parents of a child with cognitive disability may also experience trauma from witnessing their child’s distress and suffering. For Ms Jayne Lehmann and Ms Browne, this trauma compounded the grief following the tragic death of their children.¹⁵⁸

Inadequate attention to preventive health care and other health services throughout life

Inadequate attention to preventive health strategies and promotion of healthy practices can lead people with cognitive impairment, in particular, to experience the onset or exacerbation of multiple health conditions.¹⁵⁹ Higher rates of health risk factors for people with disability (high rates of smoking, poor diet, low rates of vaccination and access to dental services) cost an estimated \$15.1 billion in 2021–22. On top of this, higher rates of obesity and high blood pressure and lower rates of exercise cost an estimated \$6.9 billion in the same year.¹⁶⁰

Data published by the AIHW on health risk factors and behaviours indicates that people with disability are more likely than people without disability to:¹⁶¹

- smoke daily
- eat less than the recommended serves of fruits and vegetables each day
- consume sugar-sweetened drinks daily
- not do enough physical activity (including at work) for their age
- be overweight or obese.

Professor Trollor told us Australian disability data highlights gaps in the provision of basic health prevention methods. This includes influenza and pneumococcal vaccinations, comprehensive annual health examinations and preventive dental care.¹⁶² A Victorian population health survey suggests that people with intellectual disability also access pap tests and mammograms at a lower rate than the general Victorian population.¹⁶³ We saw this pattern repeated in the COVID-19 pandemic, as people in disability residential settings were deprioritised in the vaccine roll out.¹⁶⁴ Chapter 1, ‘Accessible information and communications’, of this volume addresses the importance of accessible public messaging for people with disability.

A review of the causes and contributors to deaths of people with disability, commissioned by the NDIS Quality and Safeguards Commission (NDIS Commission), identified a lack of proactive support for preventive health care in disability services.¹⁶⁵ Witnesses also identified a lack of

knowledge and skills among disability support workers regarding dental hygiene and identifying dental complaints.¹⁶⁶ Volume 10, *Disability services*, contains further information about how the failure to identify and respond to health support needs can result in healthcare neglect.

Witnesses expressed strong support for annual health assessments as a way to ‘support early detection of emerging diseases and improve monitoring and effective treatment of existing conditions’.¹⁶⁷

The Australian Government’s National Preventive Health Strategy acknowledges the need for ‘additional support for those who experience the greatest inequity of outcomes’ to complement whole of population programs.¹⁶⁸ The strategy identifies people with disability as a priority population.¹⁶⁹

Diagnosis and early intervention are also critical to health and other outcomes for people with cognitive disability.

Evidence at Public hearing 4 and Public hearing 9, ‘Pathways and barriers to open employment for people with disability’, explained the impacts of delayed diagnosis of autism. The Australian Senate Select Committee on Autism’s report, *Services, support and life outcomes for Autistic Australians*, identified long wait times for an autism diagnosis in the public health system as a key barrier to early intervention, particularly for people in regional and remote areas.¹⁷⁰

Early childhood is a key period when intervention can create long-term health benefits for children with disability. Early intervention to address developmental issues frequently occurs in education and other non-medical settings and is a key social determinant of health. Ms Donna Ah Chee and Dr John Boffa from the Central Australian Aboriginal Congress described how ‘during the first few years of life, interactions between genetic make-up, environment and early experience have a dramatic impact on how the brain forms’.¹⁷¹ They noted:

By the age of five, many developmental gateways for language acquisition, self-regulation and cognitive function have been passed, and a child’s developmental trajectory has already been set.¹⁷²

We heard about the links between poor oral health and systemic health issues, including a higher risk of mortality.¹⁷³ We also heard that there are few specialised oral health services,¹⁷⁴ with only 17 specialists in Australia, and access to dentists with adequate skills in engaging with people with disability is poor.¹⁷⁵

Witnesses described high rates of mental health conditions among people with cognitive disability, and the obstacles to accessing mental health services.¹⁷⁶

We received evidence that people with cognitive disability are not offered rehabilitation services to achieve or restore function. Ms Christine Regan said when her daughter Ms Erin Sheehy had a stroke, a doctor told her about a usual nine-month stroke protocol for rehabilitation, but did not offer it to Ms Sheehy.¹⁷⁷

We also heard about inappropriate referrals to palliative care. Dr AAJ described several cases where doctors referred people with cognitive disability for palliative care rather than providing them with other medical treatment.¹⁷⁸ Conversely, Professor Trollor described missed referrals to palliative care that should have been made. He said:

Despite a rapidly expanding aging population with intellectual disability and an overrepresentation of life-limiting conditions among this population, there is a paradoxical under-referral of people with intellectual disability to palliative care services.¹⁷⁹

The National Palliative Care Strategy acknowledges people with disability are ‘under-served’ by palliative care.¹⁸⁰ Its implementation plan makes increasing access to palliative care a priority.¹⁸¹ Under the implementation plan, the Department published research on the key barriers and promising approaches for improving the experience of palliative care for people with disability in Australia.¹⁸² The plan calls on states and territories to address access barriers in community and acute service settings.¹⁸³

We acknowledge the Australian Government’s National Roadmap seeks to address some of the lifetime healthcare issues raised at Public hearing 4. The National Roadmap includes more annual health assessments for people with cognitive disability through primary health care. It also includes better health services for First Nations people with disability and for people with disability from culturally and linguistically diverse communities, or regional, rural and remote communities. The findings and recommendations in our *Final report* will guide its implementation.¹⁸⁴

Ineffective communication and information sharing

The evidence provided in Public hearing 4 demonstrated the importance of open and effective communication in meeting the health needs of people with cognitive disability. This includes communication between:

- health professionals and the patient with cognitive disability
- health professionals and the patient’s family or support persons
- different health professionals and health services.

Effective communication between health professionals and people with cognitive disability is critical to reducing distress and anxiety and to improving the accessibility of health services.¹⁸⁵ Health professionals need the knowledge, skills and attitudes to enable effective communication as a matter of course.

Research conducted by Purple Orange for the Royal Commission provides further insight into communication experiences of people with disability when accessing health care. For example, an autistic person told researchers ‘[Autism] Spectrum is a communication-based disorder. It is so hard because I can talk well but I can’t always advocate for myself. People don’t get that.’¹⁸⁶ The researchers noted how access to information and communication was identified as a critical protection from violence, abuse, neglect and exploitation by autistic and deaf participants.¹⁸⁷

Techniques are available that can be used to improve communication with people with cognitive disability. These include providing material in plain English or Easy Read, conveying information by visual images and other forms of accessible communication.¹⁸⁸

Witnesses provided other examples of effective communication. For example, health professionals might ask parents of people with disability – separately or together with the person with disability – about the person’s needs and preferences and accordingly implement appropriate supports.¹⁸⁹ Without effective and respectful communication with parents, carers or support persons, health professionals are at risk of overlooking or simply not receiving important patient information. This can adversely affect health outcomes and increase stress and anxiety for people with cognitive disability.¹⁹⁰

The benefits of effective communication among health professionals are self-evident. Lack of coordination between health professionals can make it difficult for people with cognitive disability to receive continuity in health care. It can also create a risk of incorrect diagnosis and lead to ineffective or even harmful treatment.¹⁹¹

Accurate and complete record keeping is integral to continuity of care and rapid intervention in a health crisis. Evidence provided in Public hearing 4 suggested the standard of record keeping relating to patients with complex conditions is sometimes seriously deficient.¹⁹² It can be a source of great frustration for people with cognitive disability and their families and support persons.¹⁹³

Accessible information and communication are also critical for disseminating public health messages. Evidence gathered during Public hearing 5 and Public hearing 12, and associated issues papers, demonstrated a lack of clear, timely and accessible information about the COVID-19 pandemic for people with disability.¹⁹⁴

Accessible information and communication promote health literacy and supports people with disability to advocate for themselves. We heard, to be effective, accessible communication materials should be developed in consultation with people with disability.¹⁹⁵ Health strategies and policies should also be accessible to people with disability to enable participation in service planning, design, delivery and evaluation of health services. Since Public hearing 4, NSW Health has developed various Easy Read fact sheets,¹⁹⁶ and Queensland Health has evaluated the trial of a resource called Julian’s Key Health Passport.¹⁹⁷ The Australian Government has released an Easy Read version of the National Roadmap.¹⁹⁸

Further information concerning communication and accessible information can be found in Chapter 1, ‘Accessible information and communications’, of this volume.

Glynn and Orra*

‘Not treating him differently means not treating him appropriately.’

Glynn had cerebral palsy. ‘He couldn’t speak or walk without aids,’ his sister Orra told the Royal Commission, ‘but he was not intellectually disabled and was very bright.’

Glynn attended mainstream primary and secondary school and ‘participated in everything’. He loved his communication devices. The first one had a ‘Yankee accent’ but the next had an Aussie accent and his friends liked it much better.

Following school, Glynn worked as a communication accessibility assessor, rating public spaces. He assessed signage, the communication environment and whether people talked directly to him and didn’t rush the conversation.

Glynn was ‘somebody who didn’t let his disability get in the way’.

Two years ago, Glynn, in his mid-20s, began experiencing ‘a lot of pain’. Orra said, ‘He was never, never unwell so my parents took it very seriously.’

For about a month Glynn’s local GP treated him for constipation. Glynn’s health deteriorated and his parents took him to the local hospital. The staff didn’t take their concerns seriously and sent Glynn home.

Orra, who was living interstate, flew home. She was shocked when she saw Glynn and took him back to emergency. It was Christmas time and Glynn was left to wait.

‘During that time ... the staff were hanging Christmas decorations ... it just wasn’t right.’

Orra said there were constant delays in getting the tests doctors needed to diagnose Glynn.

‘I think because he wasn’t the type of person to be screaming out in pain or walloping or anything like that and because he doesn’t speak ... he was just seen as, “Oh he’s fine.”’

The hospital eventually admitted Glynn and treated him for dehydration and constipation. Late that evening, although Glynn was distressed and in pain, staff told Glynn’s parents to leave.

The next morning a specialist from another hospital saw Glynn vomit blood. He looked at Glynn's notes, saw something was seriously wrong and told staff to transport Glynn to his hospital.

Staff classified Glynn as low risk. When his condition deteriorated five minutes down the road the ambulance transporter didn't have the appropriate equipment. They turned around and asked the hospital to readmit him. The hospital refused because Glynn had already been discharged. He had to wait for another ambulance.

Orra said when they arrived at the new hospital 'things completely changed'. For the first time staff spoke to Glynn and asked him how he communicated. The nurse asked how he would like her to communicate with him.

'They put him in a room by himself and ran a series of tests that weren't even considered [by the other hospital].'

Less than 24 hours later, doctors diagnosed Glynn with stage 4 cancer and told his family he had days to live. The hospital managed Glynn's pain and extended his 'end-of-life care' to ensure everyone who wanted to visit could get there in time. When Glynn died there were about 30 people in his room, which was 'amazing for [Glynn] and [the family] as well'.

The health complaints authority investigated the first hospital's treatment of Glynn. The hospital maintained Glynn wasn't treated differently because of his disability. Orra said that was the problem.

'Not treating him differently means he wasn't given the adequate care and attention he needed.' Glynn should have been 'approached differently based on his special needs.'

Orra wants hospitals and medical practices to have their communication accessibility assessed.

If Glynn had assessed the first hospital, Orra said, 'they would have failed'.

Since the investigation the hospital has apologised and made some changes. Orra is confident Glynn would be proud his death has resulted in positive change.

* This is a de-identified narrative of an experience shared with us in a submission or private session. The person who shared their experience was not a witness. They did not give evidence, take an oath or give an affirmation. Nothing in this narrative represents a finding of the Royal Commission and any views expressed are those of the person, not of the Royal Commission.

Health system barriers

Health system challenges

The Australian health system faces a significant challenge in providing adequate health care for people with cognitive disability who live in regional, rural and remote areas.¹⁹⁹ Specialist services are often concentrated in large metropolitan centres.²⁰⁰ Delayed or lengthy emergency transfers from regional to metropolitan hospitals can seriously compromise a person's health.²⁰¹

Professor Leeder said distance from care is 'a critical variable when considering health care in Australia'.²⁰² He said the provision of health care to people in remote communities, and particularly First Nations people, can be 'compromised, if not entirely ineffective', unless issues around their access to housing, transport, food and money when leaving hospital are addressed.²⁰³ In Public hearing 4 we heard about the multiple forms of disadvantage that First Nations people with cognitive disability experience.²⁰⁴

People with cognitive disability, their parents and other family members, support persons, experts and advocates were unanimous in emphasising the critical part played by advocates. It is often parents who take on the role of advocate on behalf of their children with cognitive disability. In Public hearing 4, parents recounted their experiences as advocates for their children.²⁰⁵ We also heard from two self-advocates who explained how important it is for them to develop the skills required to make their own voices heard.²⁰⁶ Witnesses also described the importance of independent advocates to test decisions and said there was a risk of patients falling between the gaps if they did not have support.²⁰⁷

Successful advocacy can enable a person with disability to receive health services, therapies and medical assistance they would otherwise be denied. In Public hearing 6, Ms Joanna Mullins, Advocate and NDIS Appeals Support Officer at Independent Advocacy NQ, detailed the considerable difficulties ABK, a First Nations child with disability, as well as his family and she as his advocate, had in obtaining appropriate supports to assist him. She described the constraints of ABK's NDIS funding and the lack of appropriately experienced providers where he lives in far north Queensland. The child had also experienced difficulties in accessing ongoing appropriate, consistent medical care until Ms Mullins advocated for a specialised team to support his needs.²⁰⁸

Volume 9, *First Nations people with disability*, considers the multiple forms of disadvantage experienced by First Nations people with disability, particularly those living in remote and very remote areas.

Need for integration of health and disability services

A number of witnesses told us quality health care and better health outcomes for people with cognitive disability require changes to the health system itself and better integration with the disability services sector.²⁰⁹ Lack of integration between services is a systemic barrier preventing access to quality health care. We welcome the commitment by all of Australia's health ministers

to improve the interconnections between health, disability and aged care systems under the National Health Reform Agreement Long-term Health Reforms Roadmap. We look forward to seeing this translate into firm action.

Chapter 5 of this volume, 'Restrictive practices', considers how systemic drivers in disability, health and other service systems can influence the use of restrictive practices.

Volume 7, *Inclusive education, employment and housing*, Volume 10 and Volume 11 consider how the lack of integration across health care, disability and other services impacts on people with disability.

Slow implementation of initiatives to improve health care

In Public hearing 4, we heard the New South Wales Government and the Australian Government have introduced programs to improve how health services respond to the needs of people with cognitive disability.²¹⁰ We commend the New South Wales Government for establishing the Chair in Intellectual Disability Mental Health in 2009. Professor Trollor currently holds this position.

Witnesses and advocates referred to the initiatives in New South Wales and acknowledged New South Wales has been a leader in Australia.²¹¹ When asked about similar initiatives in other states and territories, Professor Trollor told us there was no precise equivalent, although there had been good initiatives in Queensland and Victoria.²¹² Dr Franklin described the Queensland initiatives in Public hearing 6. These included an 18-month clinical research project on specialised assessments and management advice provided to mainstream mental health services by the Mater Intellectual Disability and Autism Service.²¹³

In Public hearing 4, we also heard about national roundtables held in 2013, 2018 and 2019 which identified initiatives to improve the provision of health care and mental health care for people with cognitive disability.²¹⁴ However, it was recognised that implementation of these initiatives, and the subsequent development of the National Roadmap, had been somewhat slow.²¹⁵ Witnesses pointed to the need for substantially more resources to reduce the health gaps experienced by people with cognitive disability.²¹⁶

Need for data and research

Systematically collecting data relating to the health needs and health care of people with cognitive disability is fundamental to developing sound health policy.²¹⁷ Rigorous research is also essential to identify weaknesses or gaps in the health system and to design and evaluate programs to improve health outcomes for people with cognitive disability.²¹⁸

The evidence we received during Public hearing 4 exposed the current limitations of data collection at a national level. There is a scarcity of appropriately funded, targeted and reliable research on the health needs and health care of people with cognitive disability.²¹⁹

The Australian Government told us the National Disability Data Asset pilot could enable analysis of data on health care for people with disability and that Disability Reform Ministers have identified health as an initial priority area for coordinated analysis and data sharing.²²⁰ In relation to Medicare, the Australian Government also advised that the Department was continuing to develop their systems to collect the necessary patient data to support tailored quality care. This includes capturing patient disability information through the MyMedicare registration form, where patients can provide this information if they choose.²²¹

In Volume 12, *Beyond the Royal Commission*, we make recommendations to improve consistent data collection across mainstream services, including health, and to ensure an enduring National Disability Data Asset. This will strengthen understanding of outcomes for people with disability, including how people with disability access health care and their outcomes associated with the health system.

We welcome the Australian Government's commitment to funding research on intellectual disability health. In the October 2022 Budget, the government allocated \$15.9 million for a total commitment of \$23.9 million over four years from 2022–23 for the National Centre of Excellence in Intellectual Disability Health. The government indicated funding will continue beyond those four years.²²² The government has advised 'in addition to funding for the national centre, \$20 million was being made available from the Medical Research Future Fund Emerging Priorities and Consumer Driven Research Initiative from 2024–25, for research on improving the health of people with intellectual disability'.²²³ Prompt implementation of this initiative would benefit future targeted actions to improve health outcomes for people with disability.

4.5. Health professionals

We held Public hearing 10 to consider how education and training of health professionals can result in better quality health care and outcomes for people with cognitive disability.²²⁴ The hearing addressed a series of 'propositions for change' prepared by Counsel Assisting.²²⁵ These included a proposition that a standardised capability framework for cognitive disability health (framework) be developed to guide reforms to education and training in the health professions.²²⁶ Other propositions suggested the framework should apply across different health professions and be integrated into all training phases (entry level to post-graduate).²²⁷

The Commissioners' *Report of Public hearing 10: Education and training of health professionals in relation to people with cognitive disability (Report of Public hearing 10)* included findings and recommendations intended to encourage prompt action by the representative bodies of the health professions and government agencies.²²⁸ The report also sought to inform the implementation of Australian Government initiatives, particularly the National Roadmap.²²⁹

Commissioners recorded that:

we intend to monitor progress during the remaining term of the Royal Commission. We will determine what further action is required considering the responses to the Recommendations. The Royal Commission may include further findings and recommendations on this subject in the Final Report.²³⁰

We subsequently requested information on progress with implementation of the recommendations from the *Report of Public hearing 10* from the Department, health professional bodies, education providers and an accreditation authority. They responded in November 2022. The following analysis incorporates information from those responses.

Lack of systematic education and training

Witnesses attending Public hearing 4 and Public hearing 6 identified education and training as critical to reducing the health inequities faced by people with cognitive disability. The evidence showed a lack of systematic training about cognitive disability health for health professionals in all health disciplines throughout their careers.

In Public hearing 6, Professor Trollor drew attention to the lack of systematic training of medical and nursing students in health care and services for people with intellectual disability.²³¹ At Public hearing 4, Professor Trollor, and Professor Nicholas Lennox, Queensland Centre for Intellectual Developmental Disability, said national audits of curricula at undergraduate medical and nursing schools revealed limited content on the healthcare needs of people with intellectual disability.²³²

Professor Trollor referred to the 'stagnation' in teaching about cognitive disability health in medical and nursing degrees. This was despite the health gap and barriers to health care having been known for decades.²³³

In their *Report of Public hearing 10*, Commissioners referred to the results of the national audits of curricula as being consistent with other research available to the Royal Commission.²³⁴ The research has identified a lack of training of medical and other health professionals in intellectual disability health care at all stages from primary degree level to specialist training.²³⁵ Medical professionals reported they lack the knowledge, skills and confidence to work with people with intellectual disability and would like enhanced education.²³⁶ Commissioners heard this lack of systematic training in cognitive disability health extends to the dental profession.²³⁷

Commissioners found:

- Education providers of entry-level health practitioner programs do not adopt a consistent approach to teaching about the health care of people with cognitive disability (cognitive disability health). Education providers in a given health discipline vary considerably in how much they teach cognitive disability health content.²³⁸

-
- Education providers of health practitioner or postgraduate medical programs are not currently required to deliver education or training about specific competencies or capabilities in cognitive disability health. Because of this, students and trainees have variable exposure to cognitive disability health issues. Developing a capability or similar framework across health professions would help education providers to improve their programs so that future practitioners, including specialists, develop appropriate skills in cognitive disability health.²³⁹

Cognitive disability health capability framework

The *Report of Public hearing 10* made a number of findings and recommendations for the development and implementation of a cognitive disability health capability framework. We revisit each of these findings and recommendations below, analysing progress with implementation and making further recommendations that reflect our collective support for the full implementation of the report's recommendations.

Leadership and implementing the framework

In the *Report of Public hearing 10*, Commissioners proposed establishing a steering committee to develop the cognitive health capability framework (framework).²⁴⁰ The proposal took into account the collaborative processes for developing the National Roadmap and other health frameworks.²⁴¹

The report proposed the steering committee should include people with lived experience of cognitive disability and advocacy groups representing people with cognitive disability.²⁴² In our view, it is essential people with disability and their families and carers have genuine opportunities to contribute to the development of the framework by drawing on their lived experience in healthcare systems.²⁴³

The report recommended the steering committee should develop a detailed implementation plan outlining the key steps to translate the framework into the curriculum of each health profession. An implementation plan is necessary to ensure the framework is effectively and consistently applied across health professions and providers.²⁴⁴

The implementation plan should also cover development of a core set of learning resources and capability assessment tools associated with the framework to be used across educational and healthcare settings.²⁴⁵

Following Public hearing 10, the Australian Government submitted that the Department is best placed to oversee development of the framework and to convene the steering committee.²⁴⁶ However, Commissioners proposed the leadership role in the design of the framework and associated resources should be taken by the education, regulatory and professional bodies that are responsible for setting and implementing educational standards and curricula.²⁴⁷

The report emphasised those leading the process must take responsibility for an effective co-design and consultation process with people with lived experience of cognitive disability. They should also ensure comprehensive consultation between all of the bodies responsible for education and training across health professions.²⁴⁸ Commissioners considered that both the Australian Medical Council (AMC) and Medical Deans Australia and New Zealand (MDANZ) have the necessary commitment, skills, expertise and established stakeholder networks to assume this leadership role, supported by a steering committee.²⁴⁹

Commissioners did not consider that the leadership of the AMC and MDANZ would prevent the Department playing an active role in facilitating development of the framework.²⁵⁰

Commissioners recognised some education providers already incorporate, to varying degrees, cognitive disability health content in their programs, and adapt their programs to the specific requirements of particular health professions.²⁵¹

The Commissioners did not make recommendations about the specific content of the cognitive disability health curricula for the various health professions. However, Commissioners referred to the fact that the curricula for each health profession should involve people with cognitive disability. This is a powerful and effective means of changing the perceptions and attitudes of participants in education programs.²⁵²

This approach is supported by research commissioned by the Royal Commission on interventions to promote positive attitudes towards people with disability. This research looked at health and wellbeing and access to health care.²⁵³ Researchers identified a peer-reviewed study which demonstrated that effective training for changing attitudes of health professionals includes training content on the social model of disability and challenges the medical model. It should also include training delivered by a person with disability.²⁵⁴

Findings and recommendation from Public hearing 10

On the basis of this analysis, Commissioners made Finding 3 in the *Report of Public hearing 10*.²⁵⁵

- The development of a cognitive disability health capability framework is an available and critical strategy to ensure that cognitive disability competencies, curriculum content and resources are developed across health practitioner programs.
- Successful development and implementation of this framework requires the leadership of the education, regulatory and professional bodies responsible for the education and training of health professionals. It also requires the framework be co-designed with people with lived experience of cognitive disability.

Commissioners made Recommendation 1 in the *Report of Public hearing 10* that the AMC and MDANZ should take a joint leadership role to establish a steering committee to develop and co-design a cognitive disability health capability framework and associated initiatives.²⁵⁶

Assessment of progress in implementing the framework

The Department is now leading development of the capability framework, rather than the AMC and MDANZ, although both organisations are involved in the framework's development.²⁵⁷ As noted below, the Department's framework targets people with intellectual disability, excluding those with other forms of cognitive impairment. It is focused on undergraduate education instead of all training phases.

The Department has confirmed it will address the matters we examined at Public hearing 10 as it implements 'Element C: Better support for healthcare professionals to provide better care for people with intellectual disability' of the National Roadmap.²⁵⁸ Element C acknowledges the evidence provided to the Royal Commission that 'health professionals lack the knowledge, skills and appropriate attitudes required to address the health needs of people with intellectual disability.'²⁵⁹

In November 2022, the Department reported it was progressing the framework, including by:

- establishing a quarterly Intellectual Disability Education and Training Expert Advisory Group with responsibility for the National Roadmap curriculum project²⁶⁰
- establishing a drafting group of specialised personnel to support development of the framework by the end of 2023, including co-design workshops with people with intellectual disability and with families, carers and support workers²⁶¹
- developing a monitoring and evaluation framework with interim reporting.²⁶²

The Department also released its *Consultation Paper: Development of Intellectual Disability Health Core Capabilities* in November 2022.²⁶³

The AMC and MDANZ indicated they supported the Department's intention to form the Intellectual Disability Education and Training Expert Advisory Group to shape its work, and agreed this work aligns with the recommendations in the Commissioners' *Report of Public hearing 10*.²⁶⁴ In November 2022 AMC and MDANZ advised they were 'active members' of the Intellectual Disability Education and Training Expert Advisory Group and that group's work 'had advanced well over the past 12 months'.²⁶⁵

We are concerned about the Department's departure from the recommendation in the *Report of Public hearing 10* for joint leadership by the AMC and MDANZ. The evidence about past stagnation in curriculum reform underlines the implementation risks for this project.²⁶⁶ The recommendation was designed to position the two bodies to drive implementation of the framework by the various groups responsible for educational standards and curricula in health programs.²⁶⁷

AMC and MDANZ remain committed to using their leadership positions to advance the aims of the National Roadmap curriculum project and the Commissioners' recommendations.²⁶⁸ We commend the AMC and MDANZ for their ongoing leadership in this area.

With the Department concentrating on undergraduate education, we are concerned there is a lack of coordination of all of the health professional education and training reforms recommended in the *Report of Public hearing 10*. The implementation plan Commissioners recommended for embedding the framework across all training phases does not appear to have progressed.

The Department's update in November 2022 suggested it is a matter for other key stakeholders to separately progress and report on key education and training reforms under the National Roadmap.²⁶⁹

While the progress health professional education and training bodies are making is encouraging, we see benefits in the Department playing a more active coordination role. Its leadership is needed to drive the urgent improvement in workforce capability needed across both the existing and future health workforce to address the systemic neglect of people with cognitive disability in the health system.

Recommendation 6.24 Improve implementation planning and coordination for the cognitive disability health capability framework

The Australian Government Department of Health and Aged Care should:

- expand the role of the Intellectual Disability Education and Training Expert Advisory Group to develop an implementation plan for the cognitive disability health capability framework, including key steps for embedding the capabilities from the framework in curricula in education and training programs for health practitioners across all training stages
- develop a monitoring and evaluation framework to coordinate and measure delivery of the expanded capability framework and its implementation.

Scope and content of the framework

In Public hearing 4, Public hearing 6 and Public hearing 10, we heard about barriers to health care experienced by people with different types of cognitive disability. This includes people with intellectual disability, acquired brain injury, dementia and some people with autism. While much of the evidence concerned people with intellectual disability or autism, we received evidence that people with other types of cognitive disability experience similar barriers to health care.²⁷⁰

Following Public hearing 10, the Professional Association of Nurses in Developmental Disability Australia Inc objected to the broad categorisation of 'cognitive disability' in Counsel Assisting's submissions, suggesting it risks further marginalising people with intellectual disability.²⁷¹

Dr Jane Tracy, a general practitioner who leads educational activities at the Victorian Centre for Developmental Disability, Monash University and parent of an adult son with intellectual

disability and cerebral palsy, told us about her research with Professor Rachael McDonald on the health care of people with intellectual and associated developmental disabilities. This research identified the need to develop specific competencies on health risks and vulnerabilities associated with particular disabilities, such as Down syndrome and cerebral palsy.²⁷² The researchers suggested health professionals need an understanding of common disabilities, as well as knowing how to find out about less common conditions.²⁷³

The *Report of Public hearing 10* proposed that the framework should apply broadly to people with cognitive disability and address specific issues affecting people with intellectual disability.²⁷⁴

Commissioners also agreed the framework should apply to both registered and non-registered health professions providing health care to people with cognitive disabilities.²⁷⁵ The submissions made by the National Board Chairs did not identify any barrier to health professions collaborating on this initiative, whether or not they fall under the National Registration and Accreditation Scheme for health practitioners (National Scheme).²⁷⁶

Commissioners considered how to develop a framework that could apply across different health disciplines. Commissioners agreed with the accreditation authorities, AMC and Australian Dental Council, that a single framework could apply across multiple health professions. This framework would describe high-level capabilities to address common issues.²⁷⁷

To recognise the distinct role of each profession, the accreditation authorities said the framework should be supplemented by guidance material and requirements for accreditation of education and training for specific professions.²⁷⁸ For example, the Australian Nursing and Midwifery Council indicated it could specify the framework as part of the 'essential evidence' it requires education providers to provide when seeking accreditation for nursing and midwifery programs.²⁷⁹

The Australian Government submitted that the 800,000 practising registered health practitioners nationally would not benefit from education and training strategies targeted at entry-level curricula. It submitted the approach to developing the framework will need to encompass post-qualification education.²⁸⁰

Some submissions suggested the framework should adopt a tiered approach reflecting the different levels of service providers, work contexts and competencies required in caring for and treating people with cognitive disability.²⁸¹

Commissioners accepted Counsel Assisting's submission on the fundamental content that the framework should cover. This includes understanding disability and how attitudes, such as bias and prejudice, may affect decisions about health care for people with cognitive disability and result in diagnostic overshadowing. It should also address communication skills and making adjustments to enable access.

Commissioners said the framework should reflect the importance of interprofessional practice and integrated care for people with cognitive disability highlighted in Public hearing 4. In addition

to the content Counsel Assisting proposed in Public hearing 10, Commissioners agreed the framework should cover issues raised in Public hearing 6 regarding over-use and misuse of psychotropic medication to address ‘behaviours of concern’.²⁸²

Finding and recommendation from Public hearing 10

On the basis of this analysis, Commissioners made Finding 4 in the *Report of Public hearing 10* that ‘curriculum development relating to cognitive disability health must include skills in interprofessional practice and integrated care’.²⁸³

Commissioners also made Recommendation 2 in the *Report of Public hearing 10*:²⁸⁴

- The capability framework should be designed to apply to all registered and non-registered health professions and address core capabilities and profession-specific capabilities as necessary, and enhance health practitioner curricula across all training stages, including entry-level and post-graduate programs, in-service training and continuing professional development (CPD).
- The capability framework should specify the core knowledge, skills and attributes required for the provision of quality health care to people with cognitive disability, including intellectual disability.

Assessment of progress

As we noted above, the Department has narrowed the scope of the framework. It is limited to intellectual disability, not cognitive disability more broadly. It also focused on pre-registration (undergraduate) education, not education and training for health professionals at all stages of their careers.

This reflects the Department’s decision to lead a process focused on implementing the curriculum project,²⁸⁵ which is a short-term action under the National Roadmap. It does not address the full intent of the recommendations in the *Report of Public hearing 10*.

Commissioners were mindful of the overlap between the National Roadmap and the Royal Commission’s work and accepted that initiatives directed to curriculum development to improve health services for people with disability should not duplicate effort.²⁸⁶ However, Commissioners considered the framework proposed in Public hearing 10 was broader in scope than the curriculum project’s focus on entry-level (undergraduate level) education.²⁸⁷ The framework recommended in the *Report of Public hearing 10* is not being progressed as ‘an adjunct to the National Roadmap,’ despite the Australian Government’s response to Counsel Assisting’s submissions following Public hearing 10.²⁸⁸

The Department advises that the intellectual disability capability framework could be adapted across different education levels, including post-graduate education and CPD but is not part of the current project.²⁸⁹ The narrow scope of the current framework leaves a gap in the education

and training of health professionals already in the system, including those who may wish to specialise in cognitive disability health and those in clinical and managerial leadership roles.

Despite these concerns, we are encouraged by the progress evident in the Department's *Consultation Paper: Development of Intellectual Disability Health Core Capabilities*.²⁹⁰

The draft capabilities included in the consultation paper appear to address most of the core content identified in the *Report of Public hearing 10*. An exception is the consultation paper does not include a general capability for working effectively with people from diverse backgrounds. Recommendation 2(f) in the *Report of Public hearing 10* proposed that First Nations people, people from culturally and linguistically diverse communities and people from LGBTIQ+ communities be included. In our view, it is important for the framework to address the provision of health care to people with disability facing intersectional discrimination.

When developing the recommendations in the *Report of Public hearing 10*, Commissioners were also aware the Australian Government had decided not to extend the National Roadmap to autistic people.²⁹¹ Mr Simon Cotterell from the Department advised us the Australian Government had decided to keep autism programs separate.²⁹²

Four organisations representing the autism community met with the Department on 1 August 2022 to discuss the development of the National Autism Strategy and associated National Roadmap to Improve the Health and Mental Health of Autistic People.²⁹³ They favoured developing a separate autism spectrum disorder-related competency framework.²⁹⁴

We are concerned that postponing work on an autistic health capability framework until the proposed National Roadmap to Improve the Health and Mental Health of Autistic People is developed will result in unnecessary delays. We propose the Department should broaden the focus of the intellectual disability capability framework to cover cognitive impairment from autism and other forms of cognitive disability. Alternatively, the Department should urgently fund and prioritise work on a separate disability health capability framework relating to autism and other cognitive impairments.

The Department should also consider a model combining training modules and other resources for different forms of cognitive impairment. For instance, in Public hearing 6 we heard from Ms Paula McGowan about the United Kingdom's Oliver McGowan Mandatory Training on Learning Disability and Autism.²⁹⁵ This covers capabilities from two different core capability frameworks supporting people with intellectual disability and supporting autistic people. The training content covers both groups.²⁹⁶

Resourcing to develop the framework

The AMC advised that developing the capability framework will require dedicated additional funding, including for collating resources, drafting documents and managing the consultation process.²⁹⁷ The Australian Psychological Society also emphasised the need for external funding.²⁹⁸

Commissioners noted the National Roadmap initiative and the proposed framework have similar objectives. Commissioners pointed out that Australian Government funding is likely to be required to expand the scope of consultation needed to develop a framework that applies to post-graduate training. Commissioners suggested the funds the Australian Government has committed to the National Roadmap’s curriculum development initiative could contribute to implementing the capability framework.

Recommendation from Public hearing 10

On the basis of this analysis, Commissioners made Recommendation 3 in the *Report of Public hearing 10* that the Australian Government should facilitate and support the development and implementation of the framework and associated initiatives. The Australian Government should also consider allocating funding for the development of the framework and the Department should allocate funding for the development of the capability framework and provide secretariat support for the steering committee.²⁹⁹

Assessment of progress

The Australian Government has allocated \$4.7 million over four years, starting from 2021–22, to fund the curriculum project as a National Roadmap priority action, including developing the framework.³⁰⁰ However, the curriculum project is much narrower in scope than the reforms recommended in the *Report of Public hearing 10*. We reiterate that additional resourcing will be required to support the full intent of the recommendations in that report.

Recommendation 6.25 Expand the scope of health workforce capability development to include all forms of cognitive disability at all stages of education and training

The Australian Government Department of Health and Aged Care should:

- immediately expand the scope of the work on an intellectual disability health capability framework and associated resources to address all forms of cognitive disability, to apply at all stages of education and training. This expansion should include autism-specific content, and address specific healthcare issues for people with learning disability, dementia and acquired brain injury.
- allocate additional funding to support the expanded scope of health workforce capability development.

Oversight by the Health Ministers Meeting

The Commissioners' *Report of Public hearing 10* accepted that developing the capability framework will necessarily be lengthy given the requirement for wide consultation.³⁰¹

As implementation of the framework will continue beyond our reporting date, we directed a recommendation (Recommendation 5) to the Health Ministers Meeting (formerly known as the 'Health Council').³⁰² This body is the ministerial council that is constituted under section 5 of the National Scheme under Part 2 of the *Health Practitioner Regulation National Law (National Law)* which is in force in each state and territory.³⁰³ The *National Law* was enacted to create a uniform national registration and accreditation scheme for registered health practitioners.³⁰⁴

Recommendations from Public hearing 10

Commissioners made Recommendations 4 and 5 in the *Report of Public hearing 10*:

- The steering committee leading the development of the capability framework should report to the Royal Commission within eight months of the publication of the report on the progress in implementing Recommendations 1 and 2.³⁰⁵
- Beyond the life of the Royal Commission, the Health Council (now the Health Ministers Meeting) should have responsibility for further development and implementation of the capability framework and associated initiatives to enhance cognitive disability health education and training.³⁰⁶

Assessment of progress

On 9 December 2022, the Chair of the Health Ministers Meeting wrote to the Royal Commission indicating qualified support for Recommendation 5:

Health Ministers note that while the Commonwealth is leading this work, successful delivery of actions under the Roadmap will depend upon the active engagement and collaboration of all states and territories.

We consider it appropriate the Commonwealth reports to Health Ministers annually on the progress of actions under the Roadmap with relevance to Recommendation 5 of the report from Public hearing 10 of the Royal Commission, including the associated Capability Framework.³⁰⁷

This approach by the Health Ministers Meeting limits oversight and direct involvement of state and territory ministers to the scope of the National Roadmap curriculum project. We consider the Health Ministers Meeting should extend its role to the full scope of the framework we recommended. This includes coverage of all forms of cognitive disability (including autism) and all stages of training and education (including post-graduate and CPD).

Recommendation 6.26 Expand the role of the Health Ministers Meeting to monitor health workforce capability development

The Health Ministers Meeting should expand its role in monitoring progress of the intellectual disability health capability framework to encompass the expanded capability framework proposed in Recommendation 6.25. This should include annual reporting to the Health Ministers Meeting on the progress of actions.

Integrating the capability framework in all phases of health professional training

The *Report of Public hearing 10* makes specific recommendations to give effect to the capability framework at all levels of training for health professionals, as outlined below.

Review of accreditation standards and curriculum

Amending education accreditation standards to include cognitive disability health was a contentious issue raised during Public hearing 10.

The accreditation standard for a health profession is:

a standard used to assess whether a program of study, and the education provider that provides the program of study, provide persons who complete the program with the knowledge, skills and professional attributes necessary to practice the profession in Australia.³⁰⁸

Education providers must ensure students receive education and training consistent with standards for entry to practice in the student's health profession. The accreditation standards for the various regulated health professions differ in their format, content and structure, depending on the profession's specific education and training structures and needs.³⁰⁹ Each profession also has a set of competency or graduate outcome statements that articulate what is expected of graduates of a program of study. However, it is the accreditation standards that bind the education providers.³¹⁰

Reference to cognitive disability health in accreditation standards would effectively mandate curriculum changes by education providers.³¹¹ Accreditation standards were amended following development of the Aboriginal and Torres Strait Islander Health Curriculum Framework. This resulted in broad adoption of its contents in health science degrees across the country.³¹²

The *National Law* in force in each state and territory defines accreditation functions for regulated health professions. Sixteen health professions are regulated under the National Scheme.³¹³ For each regulated health profession, the National Board has assigned an accreditation authority. The authorities assess whether education programs should be accredited and monitor the programs and their providers to ensure they meet the standards.³¹⁴

In Public hearing 10, there were differing views on whether accreditation standards can and should be prescriptive about cognitive disability. A number of accreditation authorities, boards and an educational provider pointed out, with very limited exceptions, the standards do not specify patient cohorts or population groups. This is because standards are outcomes focused and deliberately do not specify a particular educational approach.³¹⁵

The report acknowledges accreditation standards are broadly framed and do not generally address the needs of particular population groups. However, in Public hearing 4, Commissioners found continued systemic neglect of the health needs of people with cognitive disability in the Australian health system. We heard compelling evidence that an important strategy to address that neglect is elevating the education and training of health professionals in cognitive disability health.³¹⁶

MDANZ accepted there is scope within the standards:

to better reflect the importance of greater recognition and understanding of the spectrums that exist within our communities and the role of informed and shared decision-making; in particular, recognising and taking into account the particular needs and circumstances of people with a spectrum of abilities, those who are especially disadvantaged.³¹⁷

National Board Chairs acknowledged there may be benefits to being more explicit about the competencies required to meet the needs of people with cognitive disabilities.³¹⁸ The AMC agreed accreditation bodies have a pivotal leadership role, and accreditation standards are a significant lever for reform.³¹⁹ The AMC was prepared to consider Professor Trollor's suggested changes to the accreditation standards for primary medical programs.³²⁰

Speech Pathology Australia and the Australian Pharmacy Council also supported a review of accreditation standards.³²¹

However, education providers did emphasise the constant pressure on curriculum developers to increase the time devoted to specific topics.³²² Dr Tracy and Professor McDonald acknowledged this 'competition for time within medical courses'. They suggested curriculum decision-makers should recognise teaching sessions and resources focused on people with cognitive disability have a 'wider relevance to population health issues', address current national health priorities and respond to social, legislative and policy changes.³²³

Commissioners were of the view that supporting the development of accreditation standards that focus on the health care of people with cognitive disability does not imply that teaching on this topic should be conducted separately from other topics. Academics who gave evidence in Public hearing 10 said it is more effective to integrate core concepts within the curriculum to enable students to develop competence over time. This helps students to apply their competencies in clinical practice and in a wide range of health settings where they will encounter people with cognitive disability.³²⁴ Dr Tracy explained that disability-specific content can not only be included in specific units but should also be readily woven into general units in medical and other curricula.³²⁵

The Australian Government proposed accreditation authorities should revise their accreditation standards to require educational curricula to equip health professionals with the competencies identified in the framework.³²⁶ To achieve this, it proposed seeking agreement with states and territories to direct professional bodies to ensure that accreditation standards include the competency framework.³²⁷ Commissioners did not think this was an available pathway to amend accreditation standards.³²⁸

The *Report of Public hearing 10* accepted Counsel Assisting's submission that accreditation bodies have a critical role in enhancing health professionals' understanding of and responses to the specific health needs of people with cognitive disability.³²⁹ The report also accepted Counsel Assisting's submission that there is scope within the accreditation standards for medical specialist degrees to better reflect an understanding of cognitive disability health.³³⁰ Commissioners inferred there is similar scope in accreditation standards in the other health disciplines.

Findings and recommendations from Public hearing 10

Commissioners made Findings 5 and 6 in the *Report of Public hearing 10*:

- Unless accreditation standards are revised, there is unlikely to be substantive change to educational curricula to incorporate enhanced training on cognitive disability health. Generalised accreditation standards are unlikely to be sufficient to ensure changes are made to curricula to embed cognitive disability health capabilities.³³¹
- The inclusion and comprehensiveness of cognitive disability health content in health practitioner programs have depended significantly on individual academics to support or 'champion' its inclusion. Curriculum content in this area is variable, inconsistent and prone to being discontinued if the champions leave or are no longer available to provide leadership. There is scope to incorporate and integrate cognitive disability health content in health practitioner programs, and to do so in a sustainable manner.³³²

Further to these findings, Commissioners made Recommendations 6, 7 and 8 in the *Report of Public hearing 10* that accreditation authorities for registered health professions, and the peak professional bodies for non-registered health professions, should:

- review and amend accreditation standards and evidence requirements where necessary to address whether cognitive disability health is sufficiently covered. If it is not, they should amend their accreditation standards or evidence requirements (as the case may be) accordingly.³³³
- encourage or mandate education providers to develop specific cognitive disability health curriculum content and deliver such content using inclusive teaching practices, involving people with cognitive disability where possible.³³⁴
- report to the Royal Commission within eight months on progress in implementing these recommendations.³³⁵

Assessment of progress

In a joint response to Counsel Assisting's submissions for Public hearing 10, National Board Chairs advised that the capability framework would need to be developed before accreditation standards can be revised. They said:

A cognitive disability health competency framework could be used by education providers and professional associations immediately to inform their entry-level, postgraduate and CPD programs; and could be used by National Boards and accreditation authorities when the next scheduled review of their competency framework is due. This would ensure timely outcomes from the development of a competency framework in cognitive disability health, as well as ensuring that the future workforce is equipped with the skills to meet the needs of this important patient cohort.³³⁶

However, some health professional bodies are already taking steps to amend accreditation standards, associated professional competencies/outcomes and curriculum content.

The Australian Dental Council has amended its professional competencies for newly qualified dental practitioners.³³⁷ Revised professional competencies were released in May 2022 and took effect as part of the council's accreditation process in 2023.³³⁸ Education providers must show the oral health needs of, and barriers to health care faced by, people with cognitive disability (and other disability types) have been considered in demonstrating each competency.³³⁹

In November 2022, the AMC advised it was completing a review of the *Standards for Assessment and Accreditation of Primary Medical Programs*, covering graduate outcome statements and medical program outcomes.³⁴⁰ Although the review will occur before the capability framework is finalised, the AMC was consulting on proposed changes to be incorporated into its accreditation standards drawing on evidence presented to the Royal Commission and progress to date on the framework.³⁴¹

The AMC advised us these changes are not specific to intellectual disability health and have a broader focus. The changes include:³⁴²

- an increased focus on the social accountability of medical schools
- stronger requirements for medical programs to meet community need
- including knowledge of a rights-based approach to health care in the graduate outcome statements.

For example, the August 2022 consultation draft Proposed Graduate Outcome Statements suggested a new outcome:

3.5 Demonstrate an understanding of the structural barriers to accessing healthcare services and apply strategies to mitigate the impact of these. This includes strategies to address inequitable health outcomes for different population groups such as

Aboriginal and Torres Strait Islander and Māori Peoples, migrant and refugee populations, patients with a disability and patients who identify as lesbian, gay, bisexual, transgender, queer, intersex, asexual and other.³⁴³

At that time, the AMC was planning discussions with accreditation authorities and health consumers about the changes in late 2022 and early 2023.³⁴⁴

The Council of Chiropractic Education Australasia (CCEA) advised it intended to review accreditation and competency standards in 2023 and consider whether cognitive disability health is sufficiently covered.³⁴⁵ CCEA's *Universal Competency Standard 1: Practicing Professionally, Criterion 1.2* applies a patient-centred approach to encompassing disability. However, CCEA believed further consideration needs to be given to ensure cognitive disability is adequately addressed.³⁴⁶

CCEA also intended to strongly encourage education providers to develop curriculum content specifically concerning cognitive disability health, and to do so in conjunction with people with cognitive disability and their families, carers or support persons. Providers should deliver the content using inclusive teaching practices. Where possible, this will be done with the involvement of people with cognitive disability and their families, carers or support persons.³⁴⁷

The Australian Dental Council, the AMC and the CCEA have taken these steps ahead of the finalisation of the capability framework, but the accreditation schemes continue to focus on general rather than particular standards. It is therefore critical for the monitoring and evaluation process of the Department to consider the effectiveness of the approaches taken by accreditation authorities in driving improvements in health practitioner education programs.

We reiterate that accreditation authorities should continue to progress implementation of Recommendations 6 and 7 from Public hearing 10, taking account of developments with the capability framework as accreditation standards come up for review. Accreditation standards are reviewed at approximately five-year intervals. Accreditation authorities that have only recently completed a review should consider mechanisms to address Recommendations 6 to 8 pending the next scheduled review.³⁴⁸

Recommendation 6.27 Establish regular progress reporting by accreditation authorities

Accreditation authorities for registered health professions and the peak professional bodies for non-registered health professions should:

- a. review and amend accreditation standards and evidence requirements where necessary to address whether cognitive disability health is sufficiently covered. If it is not, they should amend their accreditation standards or evidence requirements (as the case may be) accordingly.

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- b. encourage or mandate education providers to develop specific cognitive disability health curriculum content and deliver such content using inclusive teaching practices, involving people with cognitive disability where possible.
 - c. report annually to the Australian Government Department of Health and Aged Care on their progress in implementing this recommendation. Where accreditation authorities have only recently undertaken their five-yearly review, annual reporting should include progress on implementation planning to address this recommendation pending the next scheduled review.

Clinical placements for students and trainees

Commissioners heard about the importance of student clinical placements in preparing graduates to care for patients or clients with cognitive disability.³⁴⁹

A clinical placement is a structured period of supervised clinical experience and learning in a health or community setting.³⁵⁰ Clinical placements are an important opportunity for students to practise under supervision and develop communication and clinical skills in a professional environment.³⁵¹

Education providers and professional bodies and associations said there are limited clinical placements allowing students to care for people with cognitive disability,³⁵² although disciplines do provide placements. For example, the majority of speech pathology students have the opportunity to work with people with disability during clinical placements.³⁵³ Witnesses from each of the professions identified significant gaps in opportunities for supervised placements due to funding arrangements, including under the NDIS.³⁵⁴

Education providers supported increasing work-based experiences in cognitive disability health in both clinical and non-clinical contexts, such as disability, aged care and education settings.³⁵⁵ They agreed additional high-quality placement opportunities are needed. These should be in diverse settings where students can gain experience caring for people with cognitive disability under supervision as part of a multidisciplinary team.³⁵⁶

Experts in cognitive disability health welcomed the focus on clinical placements and agreed there should be placements in non-clinical settings. Professor Trollor said non-clinical disability settings can offer 'valuable experiences which engender greater understanding of the context of support for people with disability'.³⁵⁷ However, Dr Tracy did not support placements in non-clinical settings, such as special schools, on the basis 'all the wrong messages about difference and segregation get reinforced in these settings'.³⁵⁸

Education providers, professional associations and accreditation authorities identified funding mechanisms as a major barrier to expanding clinical placements. State and territory public hospitals are funded to provide clinical teaching and supervision under the Addendum to the National Health Reform Agreement. The Australian Government provides direct financial support

for clinical learning in community general practice settings through the Practice Incentives Program payments.³⁵⁹ However, there is limited financial support for supervision and learning in other community settings, notably aged care, disability services and community rehabilitation. This limits the scope for medical students to participate in supervised placement opportunities in those settings.³⁶⁰

Commissioners heard it can be difficult to find practising psychologists with the time to supervise trainees. Private practice clinical psychologists are apparently less willing to supervise than once was the case, in part because NDIS funding arrangements provide no incentive to undertake that responsibility.³⁶¹ Allied Health Professions Australia emphasised training opportunities in the disability sector have significantly reduced since those services were largely devolved through the NDIS.³⁶²

Education providers were seeking to enhance opportunities for students to undertake clinical placements that provide them with more comprehensive cognitive disability health training.³⁶³ Funding mechanisms are both a barrier and the most significant lever available to boost such opportunities. While acute public hospitals have been the traditional centre of clinical learning (and this is where most funding is directed), future practice will be increasingly in community and home-based settings. A key requirement is to fund supervisors for time spent in the allied health professions overseeing and training students, including funding through the NDIS.³⁶⁴

The Australian Government pointed out that the National Roadmap includes options to expand student placements in disability settings as a medium-term action.³⁶⁵ The government noted the NDIS National Workforce Plan includes an initiative to increase the number of traineeships and student placements. It also pointed out that government funding to universities supports student placements. However, it acknowledged there is 'an opportunity for the government to invest in innovative solutions to promote growth in student placements in areas of particular need, such as regional and remote communities'.³⁶⁶

Commissioners accepted Counsel Assisting's submission that, in implementing the National Roadmap, the Department is well placed to explore enhanced clinical placement opportunities in cognitive disability health, including through funding mechanisms.³⁶⁷

Commissioners accepted limited capacity to supervise placements is also a barrier. They acknowledged this is not an issue that can be resolved quickly. However, they considered implementing the cognitive disability health capability framework across health professional education and training would improve the effective supervision of students on clinical placements.³⁶⁸

Commissioners were also satisfied education providers can take more active steps to explore opportunities for student learning and development in cognitive disability health with all clinical placement providers. Accreditation authorities are well placed to encourage this.³⁶⁹

Finding and Recommendations from Public hearing 10

Commissioners made Finding 7 in the *Report of Public hearing 10*, that clinical placements do not consistently provide students with opportunities to develop skills in cognitive disability.³⁷⁰

In response, Commissioners made Recommendations 9 and 10 in the *Report of Public hearing 10*:

- Education providers should explore with clinical placement providers, across the range of settings in which clinical placements take place, increased opportunities for student learning and development in cognitive disability health, including as part of interprofessional teams.³⁷¹
- As part of the implementation of the National Roadmap for Improving the Health of People with Intellectual Disability (July 2021), the Australian Government should consider mechanisms to enhance funded supervised clinical and work-based training placements to train students in providing quality health care to people with cognitive disability. This should include enhanced financial support for clinical placement and supervision in community settings.³⁷²

Assessment of progress

The Department has advised it will defer implementing Recommendation 10 to align with the National Roadmap's four to six year timeline for 'exploring options for introducing student placements across health disciplines in disability settings'.³⁷³

MDANZ has expressed disappointment to the Department that clinical placements in disability health services are outside the scope of the Intellectual Disability Education and Training Expert Advisory Group.³⁷⁴ MDANZ and AMC said enabling clinical placements in disability health services is crucial for students to gain experience in understanding, care and treatment of patients with cognitive disability. They noted that placements are a vital part of achieving the aims of the framework, as envisaged by the Royal Commission.³⁷⁵

At the time this *Final report* is released, the National Roadmap short-term actions (one to three years) will have another year to run before the Department begins to focus on medium-term actions (four to six years). This is too long to wait for students to have increased exposure to people with cognitive disability during training through clinical placements in community settings.

Recommendation 6.28 Improve access to clinical placements in disability health services

The Australian Government Department of Health and Aged Care should make improved access to clinical placements in disability health services an immediate priority, including by:

- exploring increased opportunities for student learning and development in cognitive disability health, including as part of interprofessional teams, with education providers and clinical placement providers.
- considering mechanisms to enhance funded supervised clinical and work-based training placements to train students in providing quality health care to people with cognitive disability. This should include enhanced financial support for clinical placement and supervision in community settings.

Post-graduate training and continuing professional development

The Royal Commission received evidence, particularly in Public hearing 4 and Public hearing 6, that the supply of cognitive disability specialists is limited, in particular for adult patients.³⁷⁶

Commissioners examined the education and training that medical colleges provide relating to specialist qualifications for psychiatrists, physicians, anaesthetists, general practitioners, rural and remote medicine specialists and emergency physicians.

Each college has some relevant content on cognitive disability health in its basic and advanced training to become a medical specialist. However, the evidence indicated this training does not systematically cover the core aptitudes in cognitive disability health.³⁷⁷ Commissioners expected the colleges would participate in developing the cognitive disability health capability framework. This would allow colleges to consider the specific capabilities being developed for the framework when they review their programs and consider the degree to which the content is covered.³⁷⁸

Commissioners considered training pathways available in each medical specialty to become a specialist or develop advanced skills in intellectual or cognitive disability. Commissioners noted there was no clear pathway available in any of the specialties examined. An individual can create opportunities for sub-specialisation, but this is a challenging process.³⁷⁹

Commissioners received evidence about repeated calls for sub-specialty training in intellectual disability and mental health for psychiatrists.³⁸⁰ We also heard the Royal Australian and New Zealand College of Psychiatrists is developing a program leading to a certificate of advanced training.³⁸¹

Commissioners accepted that better career pathways are needed for aspiring disability specialists, notably in general practice, paediatrics, psychiatry, rehabilitation medicine and emergency medicine.³⁸² They were keen to support pathways for sub-speciality training in cognitive disability health but acknowledged promoting these pathways depends on the availability of funded training positions.³⁸³ Commissioners noted that a medium-term action in the National Roadmap (four to six years) is to embed training in intellectual disability health within specialist training programs. This includes working with colleges to develop curriculum for a sub-specialty or similar career pathway in intellectual disability. This action is consistent with the evidence we have received, particularly during Public hearing 10.³⁸⁴

Public hearing 10 also examined CPD opportunities for health professionals practising in six professions (medicine, nursing, dentistry and oral health, speech pathology, pharmacy and psychology). The evidence clearly indicated a lack of such opportunities, particularly in intellectual disability health.³⁸⁵

Counsel Assisting's submissions outlined *National Law* requirements for continuing professional education in each profession and the evidence about the availability and importance of CPD in cognitive disability health.³⁸⁶

National Board Chairs, education providers and the Australian Government supported, or supported in principle, a proposed recommendation that education providers and professional bodies in medicine and dentistry review their CPD programs and enhance and promote CPD in cognitive disability health.³⁸⁷ The Australian Government submitted any recommendation should also apply to the allied health and nursing professions.³⁸⁸

Finding and recommendations from Public hearing 10

Commissioners made Finding 8 in the *Report of Public hearing 10* that health professionals often lack access to relevant CPD training, particularly in the area of intellectual disability health across the medicine, nursing, dentistry, pharmacy, psychology and speech pathology professions.³⁸⁹

Commissioners made Recommendation 11 in the *Report of Public hearing 10* that the Royal Australasian College of Physicians (RACP), Royal Australian and New Zealand College of Psychiatrists (RANZCP), Australian and New Zealand College of Anaesthetists (ANZCA), Royal Australian College of General Practitioners (RACGP), Australasian College of Emergency Medicine (ACEM) and Australian College of Rural and Remote Medicine (ACRRM) should each:³⁹⁰

- develop specialised training content in cognitive disability health for different areas of specialisation, building on the capability framework and the core set of learning resources, so that future specialists can develop skills and competencies in cognitive disability health
- expand and promote pathways for sub-speciality training in cognitive disability health.

Commissioners made Recommendation 12 in the *Report of Public hearing 10* that the RACP, RANZCP, ANZCA, RACGP, ACEM, ACRRM, Australian Dental Association and professional bodies responsible for CPD in the nursing and allied health professions should each:³⁹¹

- review CPD programs in their respective health discipline or specialty to determine whether CPD for the provision of health care to people with cognitive disability, including intellectual and/or developmental disabilities, should be enhanced
- promote the development of CPD opportunities on the provision of health care to people with cognitive disability, including intellectual and/or developmental disabilities
- raise awareness of such CPD opportunities among members
- report to the Royal Commission within eight months of the publication of this Report on progress in implementing this Recommendation.

Assessment of progress

The RACGP, RACP and RANZCP reported in November 2022 they were reviewing and enhancing curricula and learning resources for specialist trainee and CPD programs to include education on cognitive disability health.³⁹²

Other colleges (including ACEM and ACRRM) acknowledged they had more work to do to ensure that their specialist training programs provide consistent, high quality education on cognitive disability health.³⁹³ ACRRM also said it would welcome opportunities to consider partnerships and collaborations with other colleges and educational institutions to provide specialist education and training opportunities to its registrars.³⁹⁴

ANZCA advised:

The Council of ANZCA has recently endorsed the inclusion of cultural safety as a key element in its CPD program. This acknowledges the essential need to improve equity regarding care for disadvantaged people within the communities served by anaesthetists and specialist pain physicians. This commitment extends to people with cognitive disability.³⁹⁵

We remain of the view that including people with disability only under broad categories in health professional educational standards and curricula is insufficient to ensure professionals have the knowledge and skills to address the barriers people with disability face in the health system. Broad categories such as 'cultural safety' may fail to communicate the inclusive language critical to change health system culture.³⁹⁶ Associate Professor Nathan Wilson said an assumption that intellectual and developmental disability is a part of cultural identity and diversity is 'fraught with difficulty because I would not say that most Australians would think that intellectual disability is part of someone's cultural diversity'.³⁹⁷

Embedding training and CPD in all specialist programs and creating curriculum content for sub-specialties in intellectual disability physical and mental health is currently a National

Roadmap medium-term action (four to six years).³⁹⁸ We urge the Department to reprioritise this task for immediate action.

Recommendation 6.29 Improve specialist training and continuing professional development in cognitive disability health care

- a. The Royal Australasian College of Physicians, Royal Australian and New Zealand College of Psychiatrists, Australian and New Zealand College of Anaesthetists, Royal Australian College of General Practitioners, Australasian College of Emergency Medicine and Australian College of Rural and Remote Medicine should each:
 - develop specialised training content in cognitive disability health for different areas of specialisation, building on the capability framework and the core set of learning resources, so that future specialists can develop skills and competencies in cognitive disability health
 - expand and promote pathways for sub-speciality training in cognitive disability health.
- b. These groups, as well as the Australian Dental Association and professional bodies responsible for continuing professional development (CPD) in the nursing and allied health professions should each:
 - review CPD programs in their respective health discipline or specialty to determine whether CPD for the provision of health care to people with cognitive disability, including intellectual and/or developmental disabilities, should be enhanced
 - promote the development of CPD opportunities on the provision of health care to people with cognitive disability, including intellectual and/or developmental disabilities
 - raise awareness of such CPD opportunities among members.
- c. The Australian Government Department of Health and Aged Care should reprioritise the National Roadmap for Improving the Health of People with Intellectual Disability action to embed training and CPD within all specialist training programs from a medium-term action (four to six years), to a short-term action (one to three years).

Other training

We acknowledge the important role played by state and territory governments in providing disability health training for the existing public health workforce. For example, the New South Wales Health Education and Training Institute offers 37 training modules relevant to cognitive disability health.³⁹⁹ In Queensland, a non-government organisation Check Up Australia offers online disability awareness training for mainstream health practitioners.⁴⁰⁰ Development of this training was funded by the National Disability Insurance Agency.⁴⁰¹

The Department is also promoting training opportunities in the care of people with intellectual disability for the existing primary health workforce through the National Roadmap Primary Care Enhancement Program.⁴⁰² It is also providing funding to build the mental health workforce's capacity to better meet the mental health needs of people with developmental disability, including autism.⁴⁰³

These training programs should complement the reforms we recommend to education and training provided by the health professional education sector for undergraduates and postgraduates, as well as continuing professional education.

Workforce participation

The participation of people with disability in clinical roles and leadership is also critical to changing attitudes and increasing understanding of disability across the health workforce. A research report commissioned by the Royal Commission and conducted by the University of New South Wales and Flinders University, the *Changing community attitudes to improve inclusion of people with disability research report*, indicates the active presence of people with disability in all levels of society, including employment, is a primary facilitator of attitude change.⁴⁰⁴

We are encouraged by the continuing efforts by the AMC and MDANZ to remove barriers to entry to the medical profession for people with disability. This includes AMC's review of a medical graduate outcome statement, and MDANZ's hosting of a special interest group regarding the admission and education of medical students with disability.⁴⁰⁵ In Volume 7, we make recommendations to address barriers to workforce participation of people with disability in open employment across all sectors, including health.

National centre of excellence in cognitive disability health

Witnesses at Public hearing 4 and Public hearing 10 offered broad support for a network of centres or a national centre of excellence on intellectual or cognitive disability health.

While centres of excellence already exist in Australia, there is no national network or strategy to support their work. Dr Tracy said existing specialist services, such as the Centre for Developmental Disability Health in Victoria, could achieve more with the support of a national network of specialised services.⁴⁰⁶ Mr James (Jim) Simpson, from the Council for Intellectual

Disability, spoke about how creating a network of specialised intellectual disability health services would support the mainstream health system to respond appropriately to people with intellectual disability.⁴⁰⁷

Professor Trollor said a national training centre and resource clearing house could develop, collate and disseminate resources for health professionals to improve practice for people with intellectual disability and autistic people.⁴⁰⁸ He said this had been a recommendation of the 2018 National Roundtable on the Mental Health of People with Intellectual Disability, with sector support at the highest level.⁴⁰⁹

Professor Bruce Abernethy, Executive Dean of the Faculty of Health and Behavioural Sciences at the University of Queensland, described the best models for health science centres of excellence. These include delivery of health care, education of future and present practitioners, research into and development of best practice, and coordination of a range of institutions.⁴¹⁰

This view is echoed in the National Roadmap, which includes short term actions for the Department to:⁴¹¹

- Consult on establishing a National Centre of Excellence in Intellectual Disability Health that leads, synthesises and disseminates research in intellectual disability health and supports the translation of research findings into practice.
- Work towards establishing a central repository for intellectual disability health resources for people with intellectual disability, their families and support providers, health students, professionals and educators. This includes shared language and concepts around human rights, communication, consent and decision-making.

The Commissioners' *Report of Public hearing 10* strongly supported the establishment of a national centre of excellence and were encouraged by the initiatives underway. We accepted Counsel Assisting's submission that 'a network of centres of excellence in the area of cognitive disability health could have multiple benefits'.⁴¹²

Finding from Public hearing 10

Commissioners made Finding 9 in the *Report of Public hearing 10* that:

Experts and education providers agree that it would be valuable to centralise and share resources to support improved education, training and practice in cognitive disability health. There is also broad support for the establishment of a network of centres of excellence or a national centre of excellence to bring together expertise and lead research in cognitive disability health to support the translation of research findings into practice nationally.⁴¹³

Assessment of progress

In September 2021, the Australian Government allocated funding for scoping and co-design to establish a National Centre of Excellence in Intellectual Disability Health. The Department has undertaken scoping and co-design of options for the National Centre of Excellence in Intellectual Disability Health in collaboration with stakeholders.⁴¹⁴ In 2023, the Department will identify an organisation to operate the centre which is expected to be operational by July 2024. The Department advised that ‘some core functions of the National Centre will need to be scaled up over time, as it obtains additional funding (such as research grants or other revenue sources)’.⁴¹⁵

We expect the National Centre of Excellence in Intellectual Disability Health to be a key leader and enabler of change. We welcome the investment and implementation activity to date. We urge the Australian Government and stakeholders to consider expanding the remit of the National Centre to cover autism and other forms of cognitive impairment in the future.

Recommendation 6.30 Expand the scope of the National Centre of Excellence in Intellectual Disability Health

The Australian Government Department of Health and Aged Care should expand the remit of the National Centre of Excellence in Intellectual Disability Health to include autism and other forms of cognitive impairment.

4.6. Person-centred care

Witnesses at Public hearing 4 consistently stressed the importance of a person-centred approach in addressing the health needs of people with cognitive disability. As Ms Margot Elliffe, a registered nurse whose daughter, Tara lives with disability, defined it:

Person-centred care means that the individual ... is the centre of the care and everything is explained to her, everything is about what would benefit her.⁴¹⁶

At the very least, a person-centred approach requires health professionals and institutions to be flexible and ready to adjust standard procedures to minimise the distress and trauma that people with cognitive disability often experience when they interact with the health system in Australia.⁴¹⁷

The following sections outline our recommendations to address current deficits in access to health care for people with cognitive disability. These recommendations focus on the national health standards, provision of adaptations and supports, and specialised services.

National health standards, charter and policies

National health standards

The Australian Commission on Safety and Quality in Health Care (ACSQHC) is an independent statutory authority that leads and coordinates national improvements in the safety and quality of health care. It works with the Australian Government, state and territory governments, private sector providers, clinicians, patients and carers to set national standards for health service safety and quality.

The ACSQHC has issued several sets of standards covering a range of health services.⁴¹⁸ The National Safety and Quality Health Service Standards (Health Service Standards) provide a nationally consistent statement of the level of care health consumers can expect. The primary aims of the Health Service Standards are to protect the public from harm and improve the quality of health service provision.⁴¹⁹

The Health Service Standards address eight areas:

- clinical governance
- partnering with consumers
- preventing and controlling infections
- medication safety
- comprehensive care
- communicating for safety
- blood management
- recognising and responding to acute deterioration.

Each standard contains criteria for safe, high-quality care and actions or strategies that health service providers may use to achieve them.⁴²⁰ The Health Service Standards were most recently updated in May 2021.

Other ACSQHC standards address care in specific settings. The National Safety and Quality Primary and Community Healthcare Standards (Primary and Community Healthcare Standards) apply to services delivering health care in a primary and/or community setting. These standards address a smaller subset of issues: clinical governance, partnering with consumers and clinical safety.⁴²¹

The Health Service Standards do not comprehensively address the needs of people with disability. There was support in Public hearing 4 for formal and more specific measurable strategies.⁴²² Current ACSQHC actions focus on systems to recognise and respond to cognitive impairment,⁴²³ in collaboration with the patient and support persons, and best practice use of antipsychotic and psychoactive medications.⁴²⁴

However, the Health Service Standards address many of the aspects of healthcare practice that will need to change to achieve equitable access to health services for people with disability. These aspects include person-centred care, health literacy, communication and shared decision-making. We suggest future updates to these standards be co-designed with people with disability.

The Primary and Community Healthcare Standards better acknowledge the different needs of people with disability. But they address them at a high level by requiring providers to include people with disability when:

- identifying patient populations at greater risk of avoidable differences in health outcomes⁴²⁵
- supporting patients to access health care⁴²⁶
- supporting the workforce to meet the individual needs of its patients.⁴²⁷

Compliance with national standards and guidelines issued by the ACSQHC is voluntary under the *National Health Reform Act 2011* (Cth) ⁴²⁸ but may be made compulsory under another law or contractual arrangement. States and territories often do this through purchasing agreements or conditions on service accreditation. Implementing the Health Service Standards is mandated under service accreditation requirements in all public and private hospitals, day procedure services and most public dental services across Australia.⁴²⁹

The ACSQHC maintains the Australian Health Service Safety and Quality Accreditation Scheme, which provides for the national coordination of accreditation processes. Under this scheme, the ACSQHC approves accrediting agencies to assess health service organisations against the Health Service Standards. Accrediting agencies also provide assessment outcomes to state and territory health departments to identify emerging issues and to the ACSQHC to inform future development of the standards.⁴³⁰

If an assessment shows that the standards are not being met, the health service organisation is given additional time to improve. If it does not improve in that time, accreditation is denied, and various sanctions may apply. These sanctions may include administrative oversight by the regulator, loss of licences and/or loss of funding. Any health service organisation that does not achieve accreditation must undergo a reassessment within 12 months to be able to continue to operate.⁴³¹

Review and revise the national health standards

We consider the ACSQHC standards to be a key vehicle to drive change in the health sector. They are nationally consistent, informed by extensive consultation and linked to existing regulatory and commissioning frameworks (including health service accreditation), and include specific strategies for implementation by health services.

In October 2021, the ACSQHC expanded its Cognitive Impairment Program. The initial focus is on improving health care for people with intellectual disability and supporting implementation

of the national standards.⁴³² The ACSQHC and the NDIS Commission are working together to increase engagement across the health and disability sectors and identify shared goals for the health care of people with disability.⁴³³ In July 2021, they released joint practice alerts for disability services providers on comprehensive health assessments and lifestyle risk factors.⁴³⁴

We recommend the ACSQHC review the Health Service Standards and the Primary and Community Healthcare Standards (Recommendation 6.31). The review needs to revise the criteria and actions in the standards to provide specifically for the delivery of safe, high-quality health care for people with disability.

The review under Recommendation 6.31 should incorporate the following elements:

- measures to enhance choice and control and support informed consent, including:
 - accessible information and communication
 - advocacy
 - supported decision-making
- adjustments required to provide health services to people with disability on an equal basis with others, including communication supports, clinical adaptations and adjustments to the physical environment
- measures to provide health services that are culturally safe and responsive to the intersectional needs and experiences of people with disability, including communication supports
- any other matter necessary to fulfil the right of people with disability to equitable access to health services, as recommended in Volume 4, regardless of whether the Disability Rights Act is legislated.

The ACSQHC's National Safety and Quality Mental Health Standards for Community Managed Organisations (Community Mental Health Standards), set in 2022, may provide a model for standards on:

- systems and processes to actively prevent violence, abuse, neglect, exploitation or discrimination and ensure equitable access to health services⁴³⁵
- programs and an environment meeting the needs of diverse consumers, including people with physical and intellectual disability⁴³⁶
- upholding the right to access advocacy and support services⁴³⁷
- supporting the consumer to make informed choices, exercise control and maximise their independence and autonomy⁴³⁸
- integrated service delivery and care coordination⁴³⁹
- minimising restrictive practices with the aim of eliminating their use.⁴⁴⁰

These standards apply to the community mental health sector. This sector consists largely of not-for-profit, non-government organisations providing rehabilitation, counselling, accommodation support and other services.

We heard extensive evidence about the health risk factors people with disability face and about unequal access to prevention and health promotion, diagnosis and early intervention and rehabilitation services. In light of this, we recommend that the ACSQHC consider how the national standards support equal access to health services throughout life.

We suggest the ACSQHC consult with the Australian Human Rights Commission (AHRC) and the NDIS Commission as part of the review. Consulting with the AHRC would ensure the updated national standards are connected to the existing national rights framework and the proposed statutory right of people with disability to equitable access to health services. It would also draw on the AHRC's experience of issuing the Guidelines on the rights of people with disability in health and disability care during COVID-19.⁴⁴¹

Australian Charter of Healthcare Rights

The Australian Charter of Healthcare Rights describes the rights of patients and other people using the Australian health system. It includes seven healthcare rights: access, safety, respect, information, partnership, privacy, and giving feedback.⁴⁴² The right to 'access healthcare services and treatment that meets my needs' is the first right in the charter and is the right described in the simplest terms.⁴⁴³

These rights are relevant to, but do not meet the same standard as, the proposed right to equitable access to health services under a Disability Rights Act. For example, the right to access under the Australian Charter of Healthcare Rights is not a right to equal access. When combined with bias in the health system, it could be seen to justify a lesser standard or reduced range of care. For example, it could allow exclusion of people with disability from population health campaigns or the decision not to offer rehabilitation or palliative care services to a patient with disability.

The charter is not legally binding but is embedded in both the Health Service Standards and the Primary and Community Healthcare Standards. These require health services to use a charter consistent with the Australian Charter of Healthcare Rights and make it easily accessible for patients, consumers, carers and families.⁴⁴⁴ In 2020 the charter was translated into 10 languages for people with cognitive impairment, as well as Easy Read and a guide.⁴⁴⁵

The ACSQHC has provided guides for consumers and health providers on the charter. The consumer guide describes the right to access largely in terms of cost and waiting times. However, it also acknowledges the barriers for people with disability posed by the physical environment.⁴⁴⁶ This interpretation could be broadened to better reflect the right to equitable access to health services for people with disability.

The guide for people with cognitive disability, released in 2020, emphasises the importance of supported decision-making in health care for people with cognitive disability.⁴⁴⁷ This guide could

also be broadened and updated in line with the health-related recommendations in this *Final report*.

Amend the Australian Charter of Healthcare Rights

We recommend the ACSQHC amend the Australian Charter of Healthcare Rights to reflect the rights of people with disability consistent with article 25 of the *CRPD*. For example, the right to access, which is currently defined as ‘healthcare services and treatment that meets my needs’, could be expanded to specify ‘the same range, quality and standard of healthcare services and treatment, which meets my needs and is provided to me on an equal basis to others’.

This would clarify that all people are entitled to equitable access to healthcare services, consistent with the statutory right to equitable access to health services in the Disability Rights Act proposed in Volume 4. Combined with the other rights in the charter, it would signal what people with disability should expect from health services. That includes choice and control, communication, adaptations and supports, and responsiveness to intersectional needs. This amendment to the charter would also connect with the detailed requirements set by the national standards.

Operational policies and protocols for support and advocacy

A support person is someone who assists a person with disability. This may be a family member, a friend or a person contracted to provide that function. If a person is contracted as a paid or formal voluntary support person, we refer to them as a ‘support worker’.

Support people can assist a person with disability to communicate with their clinicians, provide information about their medical history, advocate for adaptations, participate in decision-making and provide informed consent.

We received evidence that support people were unable to attend some aged care, disability and health settings due to COVID-19 restrictions. In Public hearing 5, we heard about a Deafblind woman with dementia and mobility issues living in an aged care facility. She experienced a significant breakdown in communication and harm to her mental health and wellbeing when she was isolated for six weeks without explanation.⁴⁴⁸ We also heard about a supported accommodation facility locked down in the absence of any COVID-19 cases. This excluded all friends and family and the informal oversight they provided, including identifying emerging health conditions or risks.⁴⁴⁹

This was not a universal experience. Professor Anne Kavanagh said:

when hospitals in Victoria banned visitors, the Victorian Government listened when people with disability said that they needed a support worker with them. The Victorian Government responded by issuing a directive that people with disability who need additional support can bring an additional person to the hospital, regardless of whether they were there for a COVID-19 related reason.⁴⁵⁰

Ensure people with disability can be accompanied by a support person

We recommend health agencies in all Australian jurisdictions review existing policies and protocols to ensure they permit people with disability to be accompanied by a support person when accessing health care. This should also be a consideration in future policies. This recommendation is intended to ensure policies and protocols are designed to protect patients from unintended adverse impacts on their care (such as those resulting from lockdowns during the COVID-19 pandemic).

While the evidence focused on operational policies and procedures, it is equally relevant to other instruments, such as public health orders. This recommendation aims to make visible and eliminate operational barriers to the proposed right under our recommended Disability Rights Act to access and use supports in making decisions, expressing will and preferences, and/or developing decision-making and self-advocacy ability (see Volume 4). See Chapter 2 of this volume for further detail about supported decision-making and Chapter 3 of this volume for further detail about disability advocacy.

Recommendation 6.31 Embed the right to equitable access to health services in key policy instruments

- a. The Australian Commission on Safety and Quality in Health Care should:
 - amend the Australian Charter of Healthcare Rights to incorporate the right to equitable access to health services for people with disability and align with the scope of this proposed right in the Disability Rights Act recommended in Volume 4, *Realising the human rights of people with disability*
 - review and revise the National Safety and Quality Health Service Standards and the National Safety and Quality Primary and Community Healthcare Standards to provide for the delivery of safe and high-quality health care for people with disability and align with the scope of the proposed right to equitable access to health services in the Disability Rights Act recommended in Volume 4
 - as part of this review, consider how the national standards support equal access to health services for people with disability throughout life, including (but not limited to) prevention and health promotion, diagnosis and early intervention and rehabilitation services.
- b. The Australian Government Department of Health and Aged Care and state and territory counterparts should review all policies and protocols to ensure people with disability are permitted to be accompanied by a support person in any health setting. This should apply at all times, including when in-person healthcare restrictions are in place, such as during COVID-19.

Adaptations and supports

Within the health sector, ‘adjustments’ is the term often used to refer to the changes and supports that can be put in place to meet the needs of people with disability. This language of ‘adjustments’ was also used by witnesses who presented evidence through our inquiry.⁴⁵¹ However, the term ‘adjustments’ or ‘reasonable adjustments’ is also a statutory term and forms part of the definition of direct and indirect discrimination in the *Disability Discrimination Act 1992* (Cth), which we examine in detail in Volume 4. For the purposes of this chapter of the *Final report*, we have adopted the language of ‘adaptations’ and ‘supports’ to refer to the changes and supports people with disability may need to access health care, to avoid confusion with the statutory definition of ‘adjustments’.

Lack of adaptations for people with disability in health settings

In Public hearing 4, people with disability and parents of children with cognitive disability told us adaptations were not discussed in health settings or not made when requested, resulting in increased anxiety and trauma.⁴⁵²

Several parents spoke of trying to be proactive and take a coordinated approach with health professionals before their children attended medical appointments or underwent procedures. Other parents spoke about how they had expressed their concerns about medical procedures with doctors at the time and requested action or adaptations.⁴⁵³ However, parents described hospital staff refusing to coordinate care with them and failing to use pre-medication to reduce distress. In some instances, this led to the use of restrictive practices and significant trauma.⁴⁵⁴ We also heard about repeated distressing experiences resulting from refusal to adapt routine procedures.⁴⁵⁵

This evidence demonstrates the failure of health staff to provide adaptations and supports. It creates unnecessary trauma for people with disability, particularly children. It also leads to avoidance of health care and abandonment of procedures.

Governments have recognised the need for supports and adaptations

The National Roadmap recognises ‘when health professionals listen to the needs of people with intellectual disability and make reasonable adjustments when delivering health care, patient experiences and healthcare outcomes are greatly improved’.⁴⁵⁶ It states:

models of care may need to incorporate a range of reasonable adjustments to reduce distress and trauma, and ensure high quality care. This may include adapting communication methods, adjusting surroundings, taking additional time, and involving support people in care provision.⁴⁵⁷

The National Roadmap includes actions to support health service providers to make adaptations and provide supports, including through guidance, education and training.⁴⁵⁸ Under the National Roadmap, the Australian Government is committed to considering changes to primary

healthcare funding models to support the extra time doctors need to provide appropriate person-centred care to people with intellectual disability.⁴⁵⁹

Evidence from Public hearing 4 demonstrated adaptations and supports are needed for people with a range of disabilities, including cognitive disability. However, the National Roadmap commitment is limited to improving the provision of adaptations for people with intellectual disability. The Australian Government has committed to developing a similar roadmap to improve the health of autistic people.⁴⁶⁰ The extent to which this will address the provision of adaptations and supports is unknown.

All people with disability may require some form of support to access health services. Government commitments to improve how and when adaptations and supports are provided should be for all people with disability, rather than just particular cohorts. The NSW Health policy directive Responding to Needs of People with Disability during Hospitalisation requires health service staff to 'make reasonable adjustments to respond to the needs of people with disability during hospitalisation'.⁴⁶¹ It gives a range of examples of adaptations and supports that may be needed. These include allowing extra time to provide support, providing information in alternative formats and adjusting communication methods.⁴⁶²

In 2016, the Queensland Office of the Public Advocate recommended:

Queensland Health should engage with all Health and Hospital Service Districts to make it a requirement for 'reasonable adjustments' to be made to enable high standards of health care to be provided to people with disability.⁴⁶³

In 2019, the Queensland Government responded that Health and Hospital Service Districts 'have been encouraged as part of the development of Disability Service Plans to consider the needs of people with disability in all areas of the organisation'.⁴⁶⁴ It said Queensland Health, as part of a trial to address individual and system-level barriers to service access, coordination and patient experience:

plans to work with all Health and Hospital Service Districts to consider the incorporation of 'reasonable adjustments' in their Disability Service Plans to meet the needs of people with a disability.⁴⁶⁵

Policy change must be supported by implementation action

Targeted implementation action is needed to ensure that policies in support of adaptations are realised. For example, in Chapter 1, we discuss the ongoing lack of access to Auslan interpreters and measures to increase supply. In Public hearing 29, the Royal Commission heard about the need for interpreters and the impact of language barriers and cultural issues on refugee migrants who may need to access psychologists.⁴⁶⁶ A 2012 review of the Queensland Health Interpreter Service found that 'nearly one half of clients did not receive an interpreter each time they visited Queensland Health in the past 12 months'.⁴⁶⁷ A later study found that just 37 per cent of patients admitted to a major metropolitan hospital who required an interpreter

actually received one. This is similar to reported rates in other facilities in Australia and overseas.⁴⁶⁸

The under-use of interpreters may be due to a lack of training for health professionals in how and when to use them, inadequate time allocated for appointments requiring an interpreter, or late appointments when an interpreter cannot wait.⁴⁶⁹ It may also reflect the perceived convenience of informal interpreters, such as family members.⁴⁷⁰

Concerns about cost and confusion about the scope of funded services under the Translating and Interpreting Service may also provide a disincentive for health services to facilitate interpreter use.⁴⁷¹ However, we note that general practitioners can claim longer appointments under the Medicare Benefits Schedule to fund consultations involving interpreters.⁴⁷² Some states and territories also operate their own interpreter services for health services, though fees may apply.⁴⁷³

The ACSQHC's Health Service Standards indicate making accredited interpreter services available is a key aspect of the requirement to tailor communication to service users.⁴⁷⁴ Policies at state and territory level support this.⁴⁷⁵ Compliance with these obligations should be a focus of monitoring and reporting under the Health Service Standards framework.

Absence of a rights-based, person-centred approach

A person-centred approach requires health professionals and institutions to be flexible and ready to adjust standard procedures to meet the needs of the individual patient. Most of the relevant commitments under the National Roadmap focus on improving guidance, training and support to healthcare providers who are responsible for implementing supports and adaptations. This is essential. However, it does not address the current lack of information for people with disability about the supports they are entitled to access, and the process for requesting them. Evidence in Public hearing 4 demonstrated the current power imbalance between people with disability and healthcare providers, which is partly driven by information asymmetry.⁴⁷⁶

Additional work is needed to ensure adaptations and supports are properly funded

The National Roadmap recognises the need to improve the provision of supports and adaptations and has committed to particular actions. This is positive. However, many of the actions are silent on the potential need for additional funding to implement supports and adaptations.

Not all adaptations require additional funding – for example, prioritising early morning or late afternoon appointment times for people with disability to avoid prolonged waiting periods. Some may require capital funding – for example, to fit out a sensory room. Others, such as longer appointment times, are likely to require ongoing funding.

The following funding mechanisms are the most relevant to adapting healthcare services:

- The **National Efficient Price** for public hospitals. This determines the amount of Australian Government funding for public hospital services, and provides a benchmark for the efficient cost of providing public hospital services.⁴⁷⁷ The Independent Health and Aged Care Pricing Authority (the Pricing Authority) determines this.
- The Tier 2 **Non-Admitted Care** classification for hospital services to patients who do not go through a formal admission process and do not occupy a hospital bed.⁴⁷⁸ The Pricing Authority also determines this and sets the level of funding for non-admitted services.
- Various **primary healthcare funding** models, including Medicare and the Indigenous Australians' Health Programme Primary Health Care Funding Model.⁴⁷⁹
- **Capital funding** for hospitals. State and territory governments are responsible for this.

The RACP submission to the Royal Commission argues that funding arrangements may present a barrier to providing adaptations.⁴⁸⁰ The RACP suggests the Pricing Authority investigate:

whether systemic cost factors associated with disability may require a separate adjustment to the National Efficient Price for this group of patients so that they have equitable access to public health care.⁴⁸¹

The Pricing Authority has previously considered this issue. During consultation on the Pricing Framework 2015–16, it reviewed cost data connected with providing adaptations in treatment of patients with intellectual disability. It decided the average cost of treating these patients was not materially above the price paid for their care.⁴⁸² However, it acknowledged the diagnosis codes used to identify these patients may not have captured all patients with an intellectual disability.⁴⁸³

The RACP submission to the Royal Commission identified gaps in routinely collected data on barriers to health care and adaptations regularly required by people with disability.⁴⁸⁴ It is possible that previous analysis of the cost of treating people with disability has not taken into account the actual cost of adaptations, such as for longer appointment times. Such adaptations are not inherent to a particular diagnosis but are determined by an individual's needs and reactions to a hospital environment, regardless of the underlying reason for their treatment.

The Pricing Authority also determines the price for 'non-admitted care'. This is care for patients who do not occupy a hospital bed. It includes care in hospital outpatient clinics, community-based clinics and services provided in patients' homes.⁴⁸⁵ The Pricing Authority is developing a new classification for non-admitted care services. The new classification will:

describe non-admitted activity according to patient characteristics and the complexity of care, to accurately reflect the costs of non-admitted public hospital services for activity-based funding and to move away from a classification based on a service and clinic that the patient attended.⁴⁸⁶

The Australian Association of Developmental Disability Medicine (AADDM) submission to the Pricing Authority on the development of this classification noted the ‘significant cost implications for health services in the provision of health care for people with [intellectual disability]’.⁴⁸⁷ These include changes to the model of care in relation to communication between the health practitioner, the person with intellectual disability and their carer. The AADDM said communication barriers affected a health practitioner’s capacity to accurately identify a diagnosis and associated comorbidities, and develop an effective treatment plan.⁴⁸⁸

As noted above, the Australian Government has committed to ‘considering’ changes to primary health care funding models to allow for extended appointment times.⁴⁸⁹ However, this commitment is limited to people with intellectual disability, and does not consider other adaptations or supports which may require additional funding.

The following steps are required to ensure government funding for health services adequately resources supports and adaptations for all people with disability:

- In future National Efficient Price determinations, the Pricing Authority should consider the costs of making adaptations for people with disability. These adaptations are not contingent on particular diagnoses but should be considered from a person-centred perspective, based on the number of people with disability accessing health services.
- The Pricing Authority should include the cost of making adaptations for people with disability as part of its work developing a new classification for non-admitted care services (which includes a costing study).
- The Australian Government should expand and accelerate the review of primary healthcare funding models to consider a broader range of adaptations required by people with disability. Adaptations are not just for people with intellectual disability, although they are a priority cohort.

One of the challenges in undertaking these costing reviews is the lack of information about the types of adaptations that are often required. We discuss these below.

Scope to provide a range of adaptations as standard practice

Adaptations should be made to minimise distress and trauma for people with disability when accessing health services.

During Public hearing 4 we heard evidence of practical and relatively low-cost adaptations to enable people with cognitive disability to access appropriate health care. These include:

- environmental modifications and aids to reduce sensory loads, such as dimmer lighting, reduced background noise and noise-cancelling headphones.⁴⁹⁰
- preparatory actions to familiarise the person with clinical environments, such as hospital tours⁴⁹¹ and animated videos.⁴⁹²

- different modes of service delivery, such as home visits, and taking a forward-looking approach to minimise distress associated with certain procedures. Examples are taking extra blood to reduce the need for additional blood draws, and undertaking multiple procedures at once if sedation is required, to decrease the number of hospital visits.⁴⁹³
- novel and flexible approaches to pre-medication, including sedation, to reduce distress and anxiety before critical medical procedures.⁴⁹⁴

Some supports can be mandated while allowing for tailored implementation

It is unacceptable that people with disability and the parents of children with disability, and other advocates, have to negotiate with health professionals for basic supports to enable quality health care. It is concerning their requests are often ignored or denied, especially when their complex health needs put them in frequent contact with the health system. It is clear adaptations are an essential part of realising substantive equality in the health system.

During Public hearing 4, Dr Jacqueline Small, an expert witness, told us it would be viable for the health system to implement supports and adaptations that are most frequently needed for people with intellectual disability. These include longer appointment times, appointments being booked at certain times of day, or using visual aids to overcome communication difficulties. In Dr Small's view, a suite of easily achieved adaptations could be identified and mandated, with scope to tailor them for the individual and their care plan.⁴⁹⁵

Resources to guide the implementation of adaptations already exist. For example, Professor Trollor said *Accessible mental health services for people with an intellectual disability: A guide for providers* was developed in 2014. It includes mental health services to support the needs of people with intellectual disability, many of which align with suggestions we heard.⁴⁹⁶ The Department funded the guide, but provided no funding for implementation.⁴⁹⁷

The Royal Commission agrees healthcare providers should proactively identify frequently needed supports and adaptations to enable people with disability to receive high quality health care. These should be:

- offered as part of standard health care, without the need for people with disability, or their parents, supporters or advocates to negotiate for them
- tailored to meet individual needs
- non-exhaustive, as an individual may need additional tailored supports or adaptations.

Implementing these supports should be mandatory across the healthcare system. Funding models should be reviewed and amended to guarantee they are available. Accessible information about supports should be made available to people with disability and their supporters. How and when to provide supports (including communication supports such as interpreters) should be addressed under the cognitive disability health capability framework and state and territory training for the existing health workforce (Recommendation 6.25).

The Australian College of Rural and Remote Medicine, for example, makes it a core competency of their specialist trainees to know how to access and work with interpreters.⁴⁹⁸

Improving disability identification and workforce capability is critical

Experience in the United Kingdom shows that it is critical to improve disability identification and workforce capability. Under the *Equality Act 2010* (UK), service providers, which include persons providing services to the public in health care, have a duty to make 'reasonable adjustments'.⁴⁹⁹ A recent review of adjustments for people with intellectual disability in acute care settings noted 'while reasonable adjustments are positive measures that can address health inequalities, they need to be supported at an organisational, system and individual level'.⁵⁰⁰

The review identified key barriers to implementing systemic adaptations. These included:⁵⁰¹

- a lack of systematic identification and flagging of people in the system, which focuses on the adaptation needed rather than the disability or condition
- limited knowledge and understanding of intellectual disability by health care professionals, which can give rise to negative attitudes and misconceptions.

A key enabler was 'the presence of a person or a healthcare professional who had special expertise in intellectual disability'.⁵⁰² These people were identified as a 'disability ward champion, a practice development nurse for people with intellectual disability and a learning/intellectual disability liaison nurse who provided training to hospital staff'.⁵⁰³

A range of reforms are needed in the Australian health system:

- Healthcare staff must identify people who need supports and adaptations.
- Healthcare staff should be confident about working with people with disability to implement appropriate supports and adaptations.
- People with disability and healthcare staff must be able to access people with specialised knowledge, such as liaison nurses or equivalent roles.

Recommendation 6.32 Increase capacity to provide supports and adaptations through improved guidance, funding and accessible information

The Australian Government and state and territory governments, in consultation with people with disability, should:

- a. identify and publish a list of frequently needed adaptations and supports (including communication supports) to enable people with disability to receive high-quality health care in all publicly funded settings. Adaptations and supports may need to be tailored to individual needs and additional supports may be required. These should include:

- environmental modifications and aids to reduce sensory loads, such as dimmer lighting, reduced background noise and noise-cancelling headphones
 - preparatory action to familiarise the person with disability with clinical environments, such as hospital tours and animated videos
 - different modes of service delivery, such as home visits, and taking a forward-looking approach to minimise distress associated with certain procedures – for instance, taking extra blood to reduce the need for additional blood draws, or undertaking multiple procedures at once if sedation is required to decrease the number of hospital visits
 - novel and flexible approaches to pre-medication, including sedation, to reduce distress and anxiety before critical medical procedures.
- b. review hospital (admitted and non-admitted care) and primary health care funding models to ensure these adaptations and supports can be implemented in all relevant settings.
 - c. disseminate information about the provision of adaptations and supports in a range of accessible formats.

Specialised services

Role for specialised disability health and mental health services

The main focus of our recommendations is to ensure people with disability have equitable access to all health services. However, we also understand there is a role for specialised services in disability health and mental health. Professor Lennox suggested the Netherlands model of having ‘intellectual disability physicians’ with specialist training could improve healthcare delivery for people with intellectual disability.⁵⁰⁴

Professor Trollor told us access to specialised intellectual disability health services in Australia varies substantially across jurisdictions. He noted they are most developed in New South Wales. He said where such services exist they form a valuable component of comprehensive health services for people with intellectual disability.⁵⁰⁵

Dr Nigel Lyons, Deputy Secretary, Health System Strategy and Planning, NSW Ministry of Health, and Dr Small described the model of specialised services being established in New South Wales under the NSW Intellectual Disability Health Service and Statewide Intellectual Disability Mental Health Hubs.⁵⁰⁶

The NSW Intellectual Disability Health Service offers comprehensive health assessment and recommendations for people with intellectual disability who have unresolved complex or chronic

health needs that cannot be met through the usual care pathways. It provides patients with:

- referrals for other health assessments and health services
- recommendations for support services
- advice on medication, diet, physical activity and social activity
- advice on managing ongoing care.

It also provides:

- capacity-building for health professionals, including webinars, skills training and other education sessions
- joint consultation, case conferences and advice on assessment or care of people with intellectual disability.

The service has a network of six teams and nine clinical positions across New South Wales.⁵⁰⁷ NSW Health allocated just under \$6 million per annum from 2018–19 to establish and improve it.⁵⁰⁸

The Statewide Intellectual Disability Mental Health Hubs in New South Wales help people with intellectual or developmental disability access appropriate mental health care. They offer:

- a combination of face-to-face support and virtual care
- specialised assessment, care planning, reporting and recommendations
- education, training and support for mental health clinicians and disability workers providing care to people with intellectual disability.

There are two hubs: one hub is for children and young people, and one for adults. The Sydney Children's Hospital Network Mental Health and Intellectual Disability Hub is a statewide service for people aged under 18 who have intellectual or autism spectrum disorders, or both, and also have mental health issues. NSW Health provides funding of \$358,483 per annum for the children's hub.⁵⁰⁹ The Statewide Intellectual Disability Mental Health Outreach Service helps adults with intellectual or developmental disability to access appropriate mental health care.⁵¹⁰ NSW Health provides funding of \$500,000 per annum for the adult hub.⁵¹¹

The Australian Government identifies this service as an example of integrated multidisciplinary care in the National Roadmap.⁵¹² Mr Simpson said NSW Health's specialised intellectual disability health teams were yet to be evaluated, but he could 'confidently predict' the Council for Intellectual Disability would advocate strongly for the New South Wales Government to extend their funding and implement them in all 15 local hospital networks.⁵¹³ He said other states and territories should fund similar specialised intellectual disability health teams.⁵¹⁴

The new NSW Health specialised intellectual disability health teams will provide a single assessment and short-term follow-up care. This is not a substitute for equal access across the board. Dr Small expressed uncertainty about how well other parts of the mainstream health

system will be able to continue to care for people with complex and chronic healthcare needs.⁵¹⁵

Specialised services can build mainstream disability health capacity

The evidence we heard from Dr Small suggests specialised services can build disability health capacity across mainstream services in two ways.

First, the investment demonstrates leadership and a commitment to safe, high quality care for people with disability. Dr Small expressed the view that the New South Wales specialised service model was already having a positive impact.⁵¹⁶ She said the work has drawn in mainstream health professionals and embedded accountability at the highest levels for improving the health of people with intellectual disability.⁵¹⁷

Second, specialised services can provide direct training and clinical consultation to their peers. Dr Small told us her team is seeking to build capacity by nurturing relationships with public health networks, delivering training sessions to general practitioners and increasing mainstream health professionals' skills with tools and other supports.⁵¹⁸ The New South Wales Government advised us the Statewide Intellectual Disability Mental Health Hubs have provided training to over 2,000 health and disability professionals since they were established in June 2020. The New South Wales Government noted 'online training has covered mental health assessment of people with intellectual disability, modifying therapeutic interventions, using sensory strategies and addressing attachment difficulties in children with autism spectrum disorder'.⁵¹⁹

Need for specialised health and mental health services for people with cognitive disability

We recommend state and territory governments fund and establish specialised health and mental health services for people with cognitive disability.

This expands on the education and training recommendations in this chapter to further build the capacity of the health workforce. In basing the proposal on the model of care in New South Wales, we intend to ensure these services are integrated within the mainstream health system, avoiding a segregated approach. There is also a strong focus on capacity-building across the health system and embedding specialised services within local hospital networks.

This recommendation is intended to apply broadly to all states and territories which are at varying stages in establishing and evaluating specialised disability health and mental health services. Where specialised services are not available, the National Centre of Excellence in Intellectual Disability Health will play a crucial role in disseminating best practice.

Under the National Roadmap, the Australian Government has committed to work with state and territory governments to develop a national network of specialised intellectual disability health services within four to six years. The network will facilitate delivering clinical services in collaboration with existing services and enable access to care for people with intellectual disability with multiple and complex needs.⁵²⁰

As a longer-term priority (seven to 10 years), the Department has committed to working with state and territory governments to expand the national network of specialised intellectual disability health services. The aim is to ensure it supports people with intellectual disability in every state and territory, including rural and remote areas.⁵²¹

In our view 10 years is too long for people with cognitive disability to wait before all governments begin to act on specialised services. A proactive approach to preventive medical treatment will begin to address the disproportionate prevalence of preventable health conditions in people with disability.⁵²² Our recommendation is designed to ensure all governments give immediate attention to investment and planning.

We recognise implementation will require extensive business and financial planning. The complexity of planning processes will depend on the nature and extent of services for people with cognitive disability already available in each jurisdiction.

Evaluation is essential to assess the impact of specialised services

Evaluation should consider the impact of specialised services on people with intellectual disability who receive direct services. It should also assess the broader impact on health professionals and the quality of care for people with disability in mainstream services.

In Public hearing 4, Dr Lyons said New South Wales specialised services will be evaluated. The New South Wales Government then advised us the Social Policy Research Centre and the Department of Developmental Disability Neuropsychiatry, University of New South Wales have started to evaluate the Statewide Intellectual Disability Mental Health Hubs.⁵²³ However, COVID-19 delayed the NSW Intellectual Disability Health Service evaluation, which is yet to commence.⁵²⁴ Dr Small noted the New South Wales specialised intellectual disability healthcare teams are still being established. She said their work must be measured against indicators to ensure the model leads to meaningful outcomes and a reduction in avoidable health gaps for people with intellectual disability.⁵²⁵

Professor Lennox identified a risk that specialised services may focus on large metropolitan centres rather than rural and regional areas.⁵²⁶ Establishing statewide hubs may help to spread the benefits across regional and remote areas. This should be assessed as part of any evaluation.

Evaluation findings should be shared across jurisdictions and made publicly available.

Recommendation 6.33 Develop specialised health and mental health services for people with cognitive disability

State and territory governments should establish and fund specialised health and mental health services for people with cognitive disability to provide:

- specialist assessment and clinical services, including preventive medicine, for people with cognitive disability and complex or chronic health and mental health needs
- training and support for health providers to build their capacity to provide safe, high-quality health care to people with cognitive disability.

These services should be delivered through a model that includes:

- specialist roles and multi-disciplinary teams embedded in local health service delivery
- statewide specialised services that can be accessed by people with cognitive disability and health professionals regardless of their location
- participation in a national network of specialised disability health and mental health services
- evaluation of the impact of specialised services and publication of evaluation findings.

Planning to implement specialised services in each jurisdiction should begin as soon as practicable and take into account existing services and needs in each jurisdiction. These changes should be introduced by September 2026.

4.7. System coordination

This section looks at our recommendation to improve Australian health system coordination to reduce systemic barriers to accessing quality health care. Volume 5 provides some examples of issues raised regarding the relationship between the NDIS and the health system.

Care coordination

Challenges navigating the system

Expert witnesses described how the complexity and fragmentation of the health system impacts people with cognitive disability. Professor Leeder noted that ‘an enterprise of this size is bound to be complex’.⁵²⁷ He described the need to integrate public and private health care and coordinate management between governments.⁵²⁸

Complexity has a disproportionate impact on people with cognitive disability. Mr Simpson said:

there are big problems across the health system for everybody ... perhaps with the exception of people who have got, you know, a very high degree of social capital. But ... for people with intellectual disability, the problems are just so much greater.⁵²⁹

In Public hearing 4, people described their experience of the health system as a revolving door of health professionals.⁵³⁰ They spoke about how the system requires them to go over the full medical history of their child and 'start again' with each new doctor.⁵³¹ In particular, witnesses spoke about the lack of continuity of care at times of transition such as from paediatric to adult services.⁵³²

People with cognitive disability feel the fragmentation of adult medical care very starkly as they transition to adult care.⁵³³ Ms Toni Mitchell told the Royal Commission about her son Joshy's transition from paediatric to adult care, starting at age 16.⁵³⁴ She said each medical specialist Joshy was seeing as a child had to send a referral letter to their adult counterpart. Each of these specialists also required a referral from their general practitioner.⁵³⁵ She said the adult specialists did not have access to Joshy's previous records and relied on her copies.⁵³⁶

Poor communication and collaboration

We heard evidence about the importance of effective communication among health providers, effective communication with patients and support people, and accurate recordkeeping. Professor Lennox said information sharing 'really improves the outcome, because it ensures the crucial information about the person sitting in front of you at the time you need it is there'.⁵³⁷ He said 'without that information, mistakes occur'.⁵³⁸

Parents described how poor communication and poor collaboration can impact health outcomes for their children with cognitive disability. Dr Kelly gave evidence health care can be compromised when there is little or no collaboration among health professionals. As an example, she spoke in detail about how, when her son Ryan was hospitalised on an interstate family trip, the hospital staff were unaware of his care plan as they had no information from his specialist team.⁵³⁹

Ms Regan observed a lack of collaboration between health professionals could result in some specialists recommending treatments that directly contradict those provided by other specialists.⁵⁴⁰

Parents and carers often attempt to take on a coordinating role. Ms Mitchell told us Joshy has had no continuity of care⁵⁴¹ and it has been up to her to provide medical support, case management and coordination, as well as to advocate for him.⁵⁴² Dr Kelly said the health system does not always acknowledge or value the central role of a parent in case management and facilitating communication among health providers.⁵⁴³ She emphasised that difficulties accessing records and information impacted her ability to coordinate care for Ryan.⁵⁴⁴

We also heard evidence about the need for greater integration of disability and health services. The NSW Ageing and Disability Commission raised long standing concerns about support provided to people with disability by health staff in hospitals.⁵⁴⁵ For example, a person with swallowing difficulties could risk choking if food and fluids provided by a hospital do not meet their mealtime requirements, or they may be unable to consume their meal due to a lack of physical support.⁵⁴⁶

Ms Lehmann agreed. She said ‘medical and nursing staff acknowledged they were unable to provide the same quality of care’ as disability support workers.⁵⁴⁷

Confusion can also arise when a person with disability is discharged back into the community. Dr AAJ is a specialist in palliative medicine and the mother of a child with severe autism. She said she was aware of cases where people with severe autism have been admitted to community respite beds staffed by disability support workers who usually cannot appropriately manage health needs.⁵⁴⁸

In the NHRA Long-term Health Reforms Roadmap, the Australian Government and state and territory governments have signalled their ambition to reduce avoidable hospital presentations, time spent in hospital and discharge delays.⁵⁴⁹

In October 2022, the Australian Government announced funding for 54 NDIS Specialised Hospital Discharge Planners and 50 Hospital Liaison Officers to help coordinate supports across systems for safe and timely discharge of people with disability. This includes speeding up discharge using increased delegation and decision-making powers to fund disability support services through individual NDIS plans.⁵⁵⁰

Developing a coordinated approach to improve quality of care

A more coordinated approach is needed to improve access to health care for people with disability. Disabled people with complex health needs should not be required to navigate a complicated and fragmented health system on their own. Parents should not be required to act as unpaid case managers to link health providers.

Professor Leeder called for health services to ‘come together around the care of the individual’.⁵⁵¹ Dr Small spoke about the need for ‘integrated care’, which she described as ‘a mechanism for bringing together health providers from different sectors, to try and break down ... some of the silos’.⁵⁵² Dr Avery argued that First Nations people with disability need an integrated approach ‘in which all parts of a healthcare system come together collaboratively in accepting joint and several responsibility for attaining improvements in their health outcomes’.⁵⁵³

The Productivity Commission confirms, if properly implemented, integrated care leads to improved health outcomes for patients and improvements in the patients’ experience of care. It can also reduce costs and increase job satisfaction for clinicians.⁵⁵⁴

The Australian Government has committed to supporting more integrated and coordinated health care for people with intellectual disability, including investigating designated care

coordinator roles. The National Roadmap for Improving the Health of People with Intellectual Disability includes improvements to My Health Record, referral pathways and case conferencing technology.⁵⁵⁵ The National Roadmap also commits the Australian Government to work with state and territory governments to explore a role for nurse coordinators to support people with disability and liaise between health and disability services.⁵⁵⁶

The Senate Select Committee on Autism recommended the Australian Government work with state and territory governments to encourage hospitals and health services to adopt measures to improve the experience of autistic people. This may include employing autism liaison officers to facilitate health services for autistic people. The Australian Government supported this recommendation in principle.⁵⁵⁷

Disability health navigators to improve system access and workforce practice

We support introducing ‘disability health navigators’ to assist people with cognitive disability and complex health issues to navigate the health system and drive practice improvement. Disability health navigators should be nurses or other qualified health professionals with experience in disability and health. They will require a deep understanding of the health system to determine whether, and how, its structures and systems could be adapted to meet the patient’s needs.⁵⁵⁸ They will coordinate care by:

- providing a clear point of contact in the local hospital network for people with cognitive disability, their support people, disability support providers and primary health services
- providing accessible information about health issues and available health services to people with cognitive disability, their support people and disability support services
- coordinating access to health services for people with cognitive disability and complex health needs, including scheduling appointments and obtaining information on a patient’s behalf
- identifying practical solutions to improve lines of communication between tertiary hospital services and primary and secondary services in the community
- providing advice to local hospital networks on implementing safe, accessible and inclusive health care for people with cognitive disability, including adjustments and communication, decision and other supports
- collaborating with NDIS Hospital Liaison Officers and Specialised Hospital Discharge Planners and disability service providers to facilitate safe and timely admission and discharge of people with cognitive disability and complex health needs.

The literature indicates creating a care coordinator role is a key strategy to improve services for people with complex health needs. Care coordinators can help adapt services to meet the needs of people with disability.⁵⁵⁹ There is also evidence care coordinators for people with chronic conditions can help to reduce emergency department presentations⁵⁶⁰ and shorten hospital stays.⁵⁶¹ This may support improved health outcomes over time.⁵⁶²

We believe disability health navigators would benefit people with cognitive disability on two levels.

First, they would support people with cognitive disability to identify available services, make decisions about their health care, and connect to those services. Even a service as simple as bundling appointments and obtaining information on a patient's behalf would significantly benefit patients with complex health needs.⁵⁶³

Second, they would drive change in the health system by championing practice improvements to meet the different needs of people with cognitive disability. They would develop practical solutions to improve lines of communication across health and disability services.

By leading change from the ground up, disability health navigators would be a key vehicle to embed the revised National Standards for Safety and Quality in Health Care in practice. This would also benefit other people with disability who are outside the target cohort for the program.

Expert witnesses in Public hearing 4 suggested disability facilitators would need to have experience in both disability and health to understand the risks that arise where the disability and health systems intersect.⁵⁶⁴ They would also need:

some level of status and knowledge and expertise to empower them within the system ... they need to be in a powerful enough position to question when wrong decisions are being made and advocate in a powerful way ...⁵⁶⁵

The research confirms organisational support and visibility are critical enablers for coordinator roles.⁵⁶⁶

The number of disability health navigators in each local hospital network should reflect the complexity of the patient cohort.⁵⁶⁷

Disability health navigators should be funded in all jurisdictions

We propose disability health navigators be jointly funded by the Australian and state and territory health departments.

A partnership approach acknowledges both levels of government have already taken steps towards a care coordinator model. We recognise the Australian Government's investment in NDIS Hospital Liaison Officers and Specialised Hospital Discharge Planners to get disability supports in place when patients are medically fit to leave hospital. We also recognise the government's commitment to investigate nurse coordinator roles under the National Roadmap.

As managers of the public hospital system, state and territory governments are responsible for giving people with disability equitable access to the mainstream health system. They also have a significant incentive to achieve more cost-effective coordinated care. The disability health navigator model is influenced by existing programs, for example, in Victoria,⁵⁶⁸ Queensland⁵⁶⁹

and Tasmania.⁵⁷⁰ These programs could be adapted to implement this recommendation. Funding from the Australian Government will help smaller jurisdictions implement the model, ensuring disability health navigators are available across the country.

Disability health navigators will be employees of local hospital networks in each state and territory. The workforce may incorporate existing disability-specific navigator roles, such as Victoria's Disability Liaison Officers. Alternatively, it may expand roles under existing navigator programs, such as Queensland's Nurse and Midwife Navigators for people with complex health needs, and Tasmania's Complex Care Coordinators for people at risk of a long hospital stay. Local hospital networks should ensure disability health navigators are highly visible within the organisation and co-located with key health service partners.

The Health Ministers Meeting is the most appropriate body to lead a cooperative national approach to implementing disability health navigators. The Health Ministers Meeting is responsible for implementing the National Health Reform Agreement (NHRA), and can use multilateral or bilateral agreements to implement reforms, including innovative models of care.⁵⁷¹ Disability health navigators are relevant to NHRA long-term priorities in integrated care, collaboration across primary health and hospitals, and health literacy.⁵⁷²

Evaluation should be consistent

We agree with the Productivity Commission that there is strength in flexible implementation to respond to local needs and resources.⁵⁷³ However, we recommend the Australian and state and territory health departments develop a common evaluation framework with shared outcomes. The evaluation framework should measure the impact of disability health navigators on:

- access to health services for people with cognitive disability
- health outcomes for people with cognitive disability
- system benefits, such as fewer hospitalisations or improved relationships that form the foundation for new models of care.

Following evaluation of the initial roll out, the disability health navigator program should be expanded to support people with other types of disability and complex health needs.

We note Victoria has committed to evaluate its COVID-19 focused Disability Liaison Officers program under the Inclusive Victoria: state disability plan (2022–2026) to inform system improvements and workforce development opportunities.⁵⁷⁴

Recommendation 6.34 Introduce disability health navigators to support navigation of health care for people with disability

Through the Health Ministers Meeting, the Australian Government and state and territory governments should:

- a. jointly fund a national workforce of 'disability health navigators' to support people with cognitive disability and complex health needs access health services and to embed safe, accessible and inclusive practice in everyday health service provision
- b. develop a national evaluation framework to assess the impact of disability health navigators and share lessons learned across jurisdictions. Evaluation findings should be published.

Endnotes

- 1 *Convention on the Rights of Persons with Disabilities*, opened for signature 30 March 2007, 2515 UTS 3 (entered into force 3 May 2008), art 25.
- 2 Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, *Report of Public hearing 4: Health care and services for people with cognitive disability*, October 2020, [181].
- 3 Exhibit 4-8, 'Statement of Professor Stephen Leeder', 12 February 2020, at [13].
- 4 Transcript, James Simpson, Public hearing 4, 25 February 2020, P-529 [1–6]; Exhibit 4-15, 'Statement of Sabrina Monaghan', 12 February 2020, at [17]; Transcript, Dr Nigel Lyons, Public hearing 4, 27 February 2020, P-723 [25–31].
- 5 Simone Reppermund, Preeyaporn Srasuebkul, Kimberlie Dean & Julian N Trollor, 'Factors associated with death in people with intellectual disability', (2019), vol 33 (3), *Journal of Applied Research in Intellectual Disabilities*, p 1.
- 6 Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, *Report of Public hearing 4: Health care and services for people with cognitive disability*, October 2020, [129]; Exhibit 4-9, 'Statement of Professor Julian Trollor', 11 February 2020, at [31–95]
- 7 Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, *Report of Public hearing 10: Education and training of health professionals in relation to people with cognitive disability*, March 2022, referring to Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, *Report of Public hearing 4: Health care and services for people with cognitive disability*, October 2020, [525].
- 8 Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, *Report of Public hearing 6: Psychotropic medication, behaviour support and behaviours of concern*, September 2020, [331–342].
- 9 Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, *Report of Public hearing 5: Experiences of people with disability during the ongoing COVID-19 pandemic*, November 2020, [96.1].
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- 12 Transcript, Cheryl Axelby, Public hearing 11, 23 February 2021, P-453 [36–38], P-464 [6–15]; Transcript, Lewis Shillito, Public hearing 11, 23 February 2021, P-463 [38–47]; Transcript, John Boffa, Public hearing 16, 20 September 2021, P-118 [21–32], P118 [18–22]; Transcript, Andrew Webster, Public hearing 16, 20 September 2021, P-168 [47]–P-169 [3], [11–13], [17–32]; Transcript, Catherine Liddle, Public hearing 16, 24 September 2021, P-468 [18–30].
- 13 Australian Institute of Criminology, *Experiences of domestic violence among women with restrictive long-term health conditions*, Report prepared for the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, May 2021; Transcript, Kathryn Fordyce, Public hearing 17, 13 October 2021, P-48 [4–9]; Transcript, Nicole Lee, Public hearing 17, 28 March 2022, P-25 [1]–P-26 [34], P-30 [28–44], P-34 [8–10]; Transcript, Catherine Dunn, Public hearing 17, 29 March 2022, P-68 [43]–P69 [26]; Transcript, Etana, Public hearing 17, 29 March 2022, P-80 [1-29]; Transcript, Ally Robins, Public hearing 17, 30 March 2022, P-203 [27–39].
- 14 Submissions of Counsel Assisting the Royal Commission following Public hearing 17, 25 January 2023, pp 163–168 [514–521].
- 15 See for example evidence in relation to the impact of negative attitudes, language and trauma on access to health care: Transcript, Jen Blyth, Public hearing 29, 24 October 2022, P-53 [10–13], P-57 [30–31]; Transcript, 'Ash', Public hearing 29, 26 October 2022, P-207 [43]–P-208 [4]; Transcript, 'Muzhgan', Public hearing 29, 27 October 2022, P-317 [41–46]; Exhibit 29-14, 'Statement of Trevor', 6 October 2022, at [7–11], [39].
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- 17 *Convention on the Rights of Persons with Disabilities*, opened for signature 30 March 2007, 2515 UTS 3 (entered into force 3 May 2008), art 25.
- 18 *Convention on the Rights of Persons with Disabilities*, opened for signature 30 March 2007, 2515 UTS 3 (entered into force 3 May 2008), art 25.
- 19 *Convention on the Rights of Persons with Disabilities*, opened for signature 30 March 2007, 2515 UTS 3 (entered into force 3 May 2008), art 26.
- 20 *Convention on the Rights of Persons with Disabilities*, opened for signature 30 March 2007, 2515 UTS 3 (entered into force 3 May 2008), art 6 (1).
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- 23 Exhibit 4-9, 'Statement of Professor Julian Trollor', 11 February 2020, at [301].
- 24 Committee on the Rights of Persons with Disabilities, *Concluding observations on the combined second and third period reports of Australia*, 22nd sess, UN Doc CRPD/C/AUS/CO/2-3, (15 October 2019), [47].
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- 29 Exhibit 4-29, 'Statement of Tania Rishniw', 5 February 2020, at [14].
- 30 Exhibit 4-8, 'Statement of Professor Stephen Leeder', 12 February 2020, at [14]; Exhibit 4-29, 'Statement of Tania Rishniw', 5 February 2020, at [21].
- 31 Exhibit 4-29, 'Statement of Tania Rishniw', 5 February 2020, at [11]; Exhibit 4-8, 'Statement of Professor Stephen Leeder', 12 February 2020, at [10].
- 32 Australian First Ministers, Addendum to National Health Reform Agreement 2020–2025, May 2020.
- 33 Exhibit 4-29, 'Statement of Tania Rishniw', 5 February 2020, at [21]; Exhibit 4-8, 'Statement of Professor Stephen Leeder', 12 February 2020, at [15]; Transcript, Stephen Leeder, Public hearing 4, 20 February 2020, P-155 [30]–P-156 [2].
- 34 Exhibit 4-8, 'Statement of Professor Stephen Leeder', 12 February 2020, at [16].
- 35 Medical Services Advisory Committee, 'What is the MBS and Medicare', *Australian Government Department of Health and Aged Care*, web page, 20 July 2016. <www.msac.gov.au/internet/msac/publishing.nsf/Content/factsheet-03>
- 36 Australian Government Department of Health and Aged Care, 'Indigenous Australians' Health Program primary health care funding model technical factsheet', Canberra, 6 November 2019.
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- 328 Noting the *National Health Practitioner Regulation Law Act 2009* (Qld) s 11(4), which provides that the Ministerial Council may give a National Board a direction relating to a particular proposed accreditation standard, or a particular proposed amendment of an accreditation standard, for a health profession 'only if (a) in the Council's opinion, the proposed accreditation standard or amendment will have a substantive or negative impact on the recruitment or supply of health practitioners; and (b) the Council has first given consideration to the potential impact of the Council's direction on the safety and quality of health care'. Queensland is the lead jurisdiction for the *National Law*, which each state and territory have enacted and implemented using an 'adoption of laws' model.
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5. Restrictive practices

Key points

- People with disability are disproportionately subjected to restrictive practices in many areas of their lives. Restrictive practices can cause physical and mental harm to people with disability. Restrictive practices include seclusion and physical, chemical, mechanical and environmental restraints. They are not consistently used as a last resort.
- Restrictive practices are used in response to 'behaviours of concern'. Behaviour is an important form of communication, particularly for people with intellectual disability and cognitive impairment. However, rather than recognising someone may be communicating pain or distress, behaviours are pathologised and labelled as 'concerning'. Restrictive practices may then be used to 'manage' behaviour.
- The definition of 'restrictive practices' is not consistent across settings and across states and territories. Regulatory frameworks that govern authorisation and use of restrictive practices in disability, health, education and justice settings are inconsistent and complex. People with disability are therefore not equally protected.
- States and territories should ensure legal frameworks are in place to reduce restrictive practices, with the aim of elimination. These should be based on a set of national principles that apply across all settings. As an immediate step, states and territories should ensure use of the most egregious restrictive practices is not permitted, including those that are punitive or prohibited.
- Legal frameworks should establish or clarify the powers and functions of a Senior Practitioner, or equivalent role, to oversee and drive down the use of restrictive practices.
- Psychotropic medication is over-used and over-prescribed to people with cognitive disability. Education and training for disability and health professionals and efforts by national commissions responsible for health care, disability and aged care are needed.
- Further research is crucial to determine what works to reduce and eliminate the use of restrictive practices.
- Little data is publicly available on the use of restrictive practices, but registered National Disability Insurance Scheme providers frequently use them. Data collection and reporting should be addressed as an immediate priority.

5.1. Introduction

In this chapter we discuss the use of restrictive practices against people with disability, particularly people with cognitive disability.

A restrictive practice is any practice or intervention that has the effect of restricting a person's rights or freedom of movement. Restrictive practices include physical, chemical, mechanical or environmental restraint, and seclusion. People with disability are subjected to restrictive practices in many settings, including schools, group homes, healthcare institutions and places of detention.

The chapter discusses restrictive practices in a human rights context and addresses the definition of restrictive practices. We explain behaviour is an important means of communication for many people with disability. We describe what we have learnt about how behaviour can be misunderstood and result in the inappropriate use of restrictive practices.

The chapter sets out the regulatory framework for the authorisation and prohibition of restrictive practices, focusing on disability service provision, health, education and justice settings. We recommend states and territories put in place stronger legal frameworks to reduce and eliminate restrictive practices.

We propose states and territories expand or create the role of a Senior Practitioner to drive the reduction and elimination of restrictive practices. The Senior Practitioner's role should include authorising and overseeing the use of restrictive practices.

We then discuss the use of psychotropic medication as a specific form of restrictive practice applied to people with disability. We recommend reforms to reduce inappropriate use.

The chapter concludes by considering research and data collection and reporting on restrictive practices. We make recommendations to strengthen the evidence base on restrictive practices and improve the quality of data collection and reporting.

5.2. Understanding restrictive practices

Restrictive practices and human rights

The routine and pervasive use of restrictive practices on people with disabilities ... is worrying. The result is the trivialisation of interfering with another person's equal rights and freedoms, which contributes to the dehumanisation of people with disability.¹

Restrictive practices are used in response to so-called behaviours of concern by people with disability. This raises questions about Australia's compliance with its obligation to respect, protect and fulfil the rights of people with disability recognised by the *Convention on the Rights of Persons with Disabilities (CRPD)* and other international human rights treaties.²

The *CRPD* does not specifically address restrictive practices, but the use of restrictive practices intersects with a number of different *CRPD* rights.³ These include:

- article 14(1), which requires States Parties to ensure that people with disability, on an equal basis with others, enjoy the right to liberty and security of the person
- article 15(1), which states that no-one shall be subjected to torture or to cruel, inhuman or degrading treatment
- article 16(1), which requires States Parties to take all appropriate measures to protect people with disability from all forms of exploitation, violence and abuse.

The United Nations Committee on the Rights of Persons with Disabilities (CRPD Committee) is the body that monitors the implementation of the *CRPD*. It has described article 14 as 'one of the most precious rights to which everyone is entitled'.⁴ However, article 14 has become one of the most controversial provisions in the *CRPD*, largely due to different views on the language imposing restrictions on the right.⁵

In 2013, the CRPD Committee expressed concern that in Australia:

persons with disabilities, particularly those with intellectual impairment or psychosocial disability, are subjected to unregulated behaviour modification or restrictive practices such as chemical, mechanical and physical restraints and seclusion, in various environments, including schools, mental health facilities and hospitals.⁶

The CRPD Committee recommended Australia 'take immediate steps to end such practices'.⁷

In 2013, the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment stated:

it is essential that an absolute ban on all coercive and non-consensual measures, including restraint and solitary confinement of people with psychological or intellectual disabilities, should apply in all places of deprivation of liberty, including in psychiatric and social care institutions.⁸

In 2019, the CRPD Committee's Concluding Observations to Australia recommended:

[Australia should] establish a nationally consistent legislative and administrative framework for the protection of all persons with disabilities, including children, from the use of psychotropic medications, physical restraints and seclusion under the guise of "behaviour modification" and the elimination of restrictive practices, including corporal punishment, in all settings, including the home.⁹

Defining restrictive practices

The use of restrictive practices is regulated at the national, state and territory levels in a range of contexts, including disability service provision and health, education and justice settings. There is no single national law on the use of restrictive practices, and states and territories regulate different categories of restrictive practices.¹⁰ There is no nationally agreed definition of a 'restrictive practice'. Nor are there agreed definitions of different types of restrictive practices.

For the purposes of this *Final report*, we have defined 'restrictive practices' as 'any practice or intervention that has the effect of restricting the rights or freedom of movement of a person with disability'. This is the definition adopted in the *National Disability Insurance Scheme Act 2013* (Cth) (*NDIS Act*).¹¹

The *National Disability Insurance Scheme (Restrictive Practices and Behaviour Support) Rules 2018* (Cth) (*NDIS Restrictive Practices Rules*) define five types of restrictive practices. They provide that a restrictive practice is a 'regulated restrictive practice' if it is or involves any of the following:¹²

- **Seclusion** – The sole confinement of a person with disability in a room or a physical space at any hour of the day or night where voluntary exit is prevented, or not facilitated, or it is implied that voluntary exit is not permitted.¹³
- **Chemical restraint** – The use of medication or chemical substance for the primary purpose of influencing a person's behaviour. It does not include the use of medication prescribed by a medical practitioner for the treatment of, or to enable treatment of, a diagnosed mental disorder, a physical illness or a physical condition.¹⁴
- **Mechanical restraint** – The use of a device to prevent, restrict, or subdue a person's movement for the primary purpose of influencing a person's behaviour but does not include the use of devices for therapeutic or non-behavioural purposes.¹⁵
- **Physical restraint** – The use or action of physical force to prevent, restrict or subdue movement of a person's body, or part of their body, for the primary purpose of influencing their behaviour. Physical restraint does not include the use of a hands-on technique in a reflexive way to guide or redirect a person away from potential harm/injury, consistent with what could reasonably be considered the exercise of care towards a person.¹⁶
- **Environmental restraint** – The restriction of a person's free access to all parts of their environment, including items or activities.¹⁷

While these definitions come from the *NDIS Restrictive Practices Rules*, we consider they adequately describe the types of restrictive practices we have heard about.

The NDIS Quality and Safeguards Commission's (NDIS Commission) *Regulated restrictive practices guide* specifies that the use of medication to suppress menstruation in response to certain behaviour of a person with disability, such as 'distress and hygiene (eg smearing)', is considered a chemical restraint. The guide also states that anti-libidinal medications, when prescribed for people with disability to address problematic sexual behaviours, are a chemical restraint.¹⁸ We discuss forced sterilisation further in Chapter 6, 'Involuntary sterilisation'.

Witnesses at Public hearings described restrictive practices in a variety of ways. For example, at Public hearing 6, 'Psychotropic medication, behaviour support and behaviours of concern', Professor Leanne Dowse, Professor of Disability Studies and Chair of Intellectual Disability and Behaviour Support at the University of New South Wales, said that restrictive practices could be viewed as a 'deprivation of liberty' when viewed in a human rights context.¹⁹

In Public hearing 4, 'Health care and services for people with cognitive disability', we heard from Ms Jacqueline Mills, Managing Director of Microboards Australia, and mother of an adult son with Angelman Syndrome. Ms Mills spoke about the use of restrictive practices on people with disability in health care. She expressed the view that restrictive practices are 'neither good nor bad. It's the context in which they're used that makes them okay or not okay for a person.'²⁰ Ms Mills gave the example of hospital staff's reluctance to help her strap her son's hands to prevent him removing a canula being used to administer life-saving antibiotics.²¹

At Public Hearing 3, 'The experience of living in a group home for people with disability', Dr Claire Spivakovsky, Senior Lecturer in Criminology in the School of Social and Political Sciences at the University of Melbourne, expressed the view that restrictive practices are 'forms of violence and abuse' against people with disability.²² She said they include 'disability-specific lawful violence' because they are permissible under legislation and only apply to people with disability.²³

In its submission to the Royal Commission, National Disability Services, the peak group for disability service providers, said when 'used properly, restrictive practices can reduce the risk of harm to a person or the people around them'.²⁴

Regardless of how restrictive practices are described, there is general agreement that they should occur in very limited circumstances, as a last resort. They should also be used in the least restrictive way for the shortest time possible and only where their use is proportionate and justified in order to protect the safety or rights of the person with disability or others who may be at risk.

Behaviour and restrictive practices

Restrictive practices are often used as a response to behaviour which is perceived as difficult to control. Some witnesses referred to behaviours of this kind as 'behaviours of concern'. Others preferred 'challenging behaviours', while yet others opted for a different, less judgmental, description.

The NDIS Quality and Safeguarding Framework (NDIS Framework) states:

['Behaviours of concern' are behaviours] of such intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy. They also include behaviour that is likely to seriously limit the use of, or result in, the person being denied access to services or ordinary community facilities.²⁵

At Public hearing 6, Dr Catherine Franklin, Director and Consultant Psychiatrist at the Mater Intellectual Disability and Autism Service in Brisbane, told us 'challenging behaviours' can include verbal, physical or sexual aggression, self-injury and property destruction.²⁶

It is critical to recognise that behaviour is an important way for people with cognitive disability to communicate. Dr Franklin explained that 'challenging behaviour' may be the sole form of communication for some people, in particular those who have limited verbal communication.²⁷ She said the behaviour may communicate physical or mental health conditions, or environmental or psychological issues such as pain, unhappiness, sensory difficulties or abuse.²⁸

This evidence is supported by research we commissioned from the University of Melbourne, University of Technology Sydney and University of Sydney, *Restrictive practices: A pathway to elimination* (*Pathway to elimination* report). It described 'behaviours of concern' as:²⁹

- a means of communication, particularly a way to communicate distress
- a response to difficult environments or situations, including a form of resistance or protest – or, in other words, adaptive behaviours to maladaptive environments.

Disability and health professionals and other staff engaging with people with disability across various settings may not recognise that some of these behaviours may be attempts at communication. Rather than trying to understand what is being communicated, restrictive practices are sometimes used to respond to and 'manage' the behaviour of people with disability.

In Public Hearing 6, we heard that interventions of this kind frequently breach the human rights of people with disability. We also heard such interventions may result in the 'behaviours of concern' escalating because the underlying issue is unaddressed.³⁰

In a private session, 'Stu' said he did not want other young people in youth detention to experience restrictive practices in response to their behaviour:

I don't want to see others go through this. And if there was anything that came of this, from my part of it, it would be to make sure that if a kid goes in [to youth detention], shows a certain series of issues like anger issues or whatever, [their response] is not just, 'He's being difficult. Let's medicate him.'³¹

Ms Jennifer Cullen is the CEO of Synapse, a national organisation that supports and advocates for people with brain injury in Australia. At Public hearing 32, 'Service providers revisited', she gave evidence about how 'external systems' label First Nations people with disability as having behaviours of concern because there is a 'misunderstanding of how behaviour is applied within our cultural context'.³² She said when external systems ask or tell Synapse a restrictive practice is needed for a First Nations person with disability, this direction is coming from someone who does not know the person. It might be an external support coordinator or the Public Guardian.³³ Ms Cullen observed:

Not once have we ever, ever stated that someone has a behaviour of concern or a challenging behaviour. We understand it within the context of who that mob is, where they are from and what that particular behaviour might mean. It's the external systems that forces our people to have restrictive practices applied, and that's where it becomes incredibly dangerous. Because we are taking away understanding the essence of culture and how it shows up in the way in which we behave.³⁴

In Public hearing 6, witnesses questioned terminology such as 'behaviours of concern' and 'challenging behaviours', or at least acknowledged that the use of these terms may be problematic.³⁵ Dr Franklin described the tendency to use 'challenging behaviour' as a diagnostic label, locating the problem solely with the individual.³⁶ Professor Dowse stressed that expressions like 'behaviours of concern' may be associated with clinical or service-type responses. They do not reflect what people with disability understand as their own lived experience.³⁷ The *Pathway to elimination* report noted that 'behaviours of concern' is a socially constructed concept, in which service provider staff interpret a particular behaviour as dangerous, frightening, distressing or annoying based on dominant social attitudes and norms.³⁸

Louis was rolling around in bed and hitting his head against the rails. He was perceived to be agitated or delirious. In-fact, he was bored and unable to communicate what he wanted to do.³⁹

Some witnesses appearing at Public hearing 6 suggested what was said to be more appropriate alternative terminology. Suggestions included 'behaviours of protest', 'behaviours of harm', 'behaviours of resistance' or 'behaviours of escalation'.⁴⁰

At Public hearing 32, Ms Hayley Dean, CEO of Melba Support Services, a disability support service in Victoria, supported use of the term ‘behaviours of protest’. Ms Dean said she considers all behaviour as a form of communication. She described this type of behaviour as a protest by a person with disability ‘against their environment for whatever reason’.⁴¹ This is consistent with submissions from some disability advocacy groups, raising concerns about current terminology and proposing alternative language.⁴² However, there was no clear consensus in the evidence or in submissions to the Royal Commission as to the preferred terminology.

In this *Final report*, we have used the term ‘behaviours of concern’. We acknowledge this term has its limitations and there are well-founded concerns about the manner in which the expression is sometimes used or interpreted. However, we recognise it is a commonly used expression and our use of it should not be understood as implying that the behaviour is the fault of the person concerned.

Commissioners Rhonda Galbally AC and Alastair McEwin AM consider ‘behaviours of concern’ a pejorative expression and a social construct that implies the person with disability is at fault for their behaviour. Commissioners Galbally and McEwin instead prefer the expression ‘behaviour seen as concerning’. To these Commissioners, this wording reflects the social and environmental factors that may contribute to the behaviour of a person with disability, including when this behaviour involves reactions – for example, to being in pain.

Australia’s developing approach

There have been several key developments in Australia’s approach to the use of restrictive practices towards people with disability in the past ten years. These include the release of the National Framework for Reducing and Eliminating the Use of Restrictive Practices in the Disability Services Sector (National Framework) and the NDIS Framework.

National Framework for Reducing and Eliminating the Use of Restrictive Practices in the Disability Services Sector

In 2014, the National Framework was endorsed by Australian, state and territory government ministers.⁴³ The key objective of the National Framework is to reduce, and ultimately eliminate, the use of restrictive practices in disability services, in accordance with Australia’s obligations under the *CRPD*.⁴⁴

The National Framework:

focuses on the reduction of the use of restrictive practices in disability services that involve restraint (including physical, mechanical or chemical) or seclusion. It aims to contribute to the promotion and full realisation of all human rights for people with disability, including liberty and security of the person and freedom from exploitation, violence and abuse, in accordance with Articles 14 and 16 of the *CRPD*. Restrictive practices should only be used where they are proportionate and justified in order to protect the rights or safety of the person or others.

The National Framework establishes a national approach to addressing the use and reduction of restrictive practices by disability service providers across a range of disability service sector settings, including institutional and community-based care. Whilst some jurisdictions have legislation or policy that regulate the use of restrictive practices, minimum requirements in relation to restrictive practices, including reviews and monitoring, are not explicitly identified in every State and Territory.⁴⁵

The National Framework attempts to set out minimum requirements on restrictive practices across Australia by highlighting the need for restrictive practices to be:⁴⁶

- used only following a formal process of assessment, planning and approval, relying on evidence-based risk assessments from appropriately qualified professionals
- proportionate and justified by the need to protect the rights or safety of the person or others
- tailored to the person's needs in accordance with a behaviour support plan
- subject to monitoring, reporting and review.

The National Framework acknowledged 'disability services are sometimes challenged to provide safe and therapeutic services for clients who have complex high support needs, as well as providing the safest possible work environment for staff'.⁴⁷ Nonetheless, the National Framework states 'it has been recognised internationally and domestically that restrictive practices can be significantly reduced and, in many cases, eliminated'.⁴⁸

NDIS Quality and Safeguarding Framework

In December 2016, the Disability Reform Council released the NDIS Framework.⁴⁹

The NDIS Framework recognises that in the past, restrictive practices were often used as a 'first line of response for people with behaviours of concern'. There was clear evidence the routine use of restrictive practices to control behaviour had often been harmful and had actually exacerbated the behaviour.⁵⁰

The NDIS Framework outlines the importance of NDIS provider registration. The NDIS Framework also explains the role of the NDIS Senior Practitioner who leads the NDIS Commission's behaviour support function. It provides that the use of restrictive practices must occur within the context of a positive behaviour support plan. It specifies that although authorisation of restrictive practices will remain with states and territories, the aim is to work towards national consistency of authorisation schemes.⁵¹

The NDIS Framework sets out the elements of a comprehensive approach to reducing and eliminating restrictive practices. It provides that 'the NDIS should move toward a system in which the use of restrictive practices in response to behaviours of concern occurs by exception'.⁵²

The NDIS Framework states that Commonwealth legislation:

will set out the key principles around the use of restrictive practices, including that the intervention is the least restrictive response available, is used only as a last resort, and that the risk posed by the proposed intervention is in proportion to the risk of harm posed by the behaviour of concern. Relevant state and territory legislation will specify the conditions that must be met for the use of a restrictive practice to be approved in a positive behaviour support plan.⁵³

The development of the current regulatory framework to restrictive practices under the NDIS, which we discuss in Section 5.3, followed the release of the NDIS Framework. The NDIS Commission was assigned a range of functions in relation to restrictive practices and behaviour support.⁵⁴ We discuss the NDIS Commission's role regarding restrictive practices further in Volume 10, *Disability services*.

Nationally consistent authorisation of restrictive practices

The NDIS Framework states consistency should apply across each jurisdiction's authorisation arrangements and states and territories should work towards this over time.⁵⁵ The NDIS Commission is responsible for assisting states and territories to develop a regulatory framework on restrictive practices in line with the National Framework and the *CRPD*.⁵⁶

The NDIS Commission led the development of Draft Principles for Nationally Consistent Authorisation of Restrictive Practices (Draft Principles for Consistent Authorisation).⁵⁷ At the July 2020 meeting of Commonwealth, state and territory Disability Ministers, all states and territories other than Queensland endorsed these principles. Queensland has provided 'in-principle support' as it continues to assess how it would apply the rules.⁵⁸

The Draft Principles for Consistent Authorisation can be summarised as follows:⁵⁹

- Legislation should specify authorisation arrangements for restrictive practices and promote the reduction and elimination of restrictive practices.
- Authorisation arrangements and systems underpinning them should aim for positive outcomes for people with disability subjected to restrictive practices, with a view to reducing and ultimately eliminating those practices.
- People with disability subjected to restrictive practices should have the same protections and rights to be free from abuse, neglect and exploitation, regardless of their disability, age and place of residence.
- People with disability and their support networks should be actively supported in making decisions about the use of restrictive practices.
- Authorisation decisions should be informed by independent advice from experts in positive behaviour support and restrictive practices.

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- Authorisation frameworks should ensure any conflicts of interest between key parties involved in decision making are effectively managed.
 - Authorisation arrangements should promote independence and dignity of risk, while also considering the interests and protection of rights of the person with disability.
 - Decisions made on the use of restrictive practices should be reviewed.
 - Authorisation arrangements should be streamlined and take into account the impact of administrative burden on providers.
 - The Australian Government and state and territory governments should work together to apply these principles, using the NDIS governance arrangements to monitor progress in achieving national consistency.

At Public hearing 32, NDIS Quality and Safeguards Commissioner (NDIS Commissioner) Ms Tracy Mackey confirmed the NDIS Commission continues to work with states and territories on national consistency.⁶⁰ She said several changes had been made to state and territory authorisation processes since September 2020.⁶¹

The NDIS Commission's Senior Practitioner Dr Chan, considers that the authorisation processes in Victoria, South Australia, the Australian Capital Territory and the Northern Territory now align with the principles for nationally consistent authorisation of restrictive practices, while the authorisation processes in New South Wales, Queensland, Western Australia and Tasmania currently partially align with the principles.⁶²

We discuss these authorisation processes further in the next section.

5.3. Regulation of restrictive practices

It is not uncommon for [restrictive practices] to be justified on the grounds of protecting the rights and safety of staff, without a deep consideration of less restrictive alternatives that respect the rights of people with disability.⁶³

Restrictive practices affect the freedom of the person with disability. Decisions about whether restrictive practices can be used must involve a weighing of this consideration against the necessity of restrictive practices in limited circumstances to ensure the safety of the person with disability and others.

Some laws, policies and procedures authorise the use of restrictive practices, but only in specified circumstances. Typically these provisions set out:

-
- the circumstances in which restrictive practices can be used
 - the person, entity or procedure for authorising use.

An alternative approach is to prohibit the use of particular kinds of restrictive practices or their use in particular circumstances. A prohibition may be imposed if restrictive practices are considered to pose an unacceptable risk of harm because of:

- the type of practice
- the combination of practices
- the situation in which they are being used
- the characteristics of a person they are to be used on.

An example of the first approach is the *Mental Health Act 2016* (Qld), which authorises use of mechanical restraint and seclusion but only if there is no other reasonably practicable way to protect the patient or others from physical harm.⁶⁴ An example of a prohibition is the Chief Psychiatrist's policy, endorsed by the Queensland Department of Health, which prohibits a person being secluded while also mechanically restrained.⁶⁵

Since an authorisation operates within the framework of an express or implicit prohibition, in practice, the two approaches tend to merge.

The Australian Law Reform Commission (ALRC) in its final report, *Equality, capacity and disability in Commonwealth laws*, observed 'there is substantial discrepancy in the regulation of restrictive practices across jurisdictions, and the numerous frameworks conspire to make the legal framework in this area exceedingly complex'.⁶⁶ The discussion below outlines the legal frameworks for restrictive practices in disability services and health, education and justice settings.

The NDIS and disability services

The *NDIS Restrictive Practices Rules* govern the authorisation and use of regulated restrictive practices by registered NDIS providers towards a person with disability.⁶⁷ The *NDIS Restrictive Practices Rules* operate concurrently with state and territory laws and policies. They must also be read together with any other mechanism regulating those restrictive practices in the state or territory where the provider operates and provides services for a person with disability.

We have referred in Section 5.2 to the definition of 'regulated restrictive practice' in the *NDIS Restrictive Practices Rules*. This definition is narrower than the definition of 'restrictive practice' in the *NDIS Act*. The latter is defined as 'any practice or intervention that has the effect of restricting the rights or freedom of movement of a person with disability'.⁶⁸ Accordingly, some restrictive practices within the *NDIS Act* definition are not regulated by the *NDIS Restrictive Practices Rules*. Unless the authorisation and use of those practices are regulated by state or territory law, there are no restrictions on their use beyond those imposed by the general criminal or civil law.

The *NDIS Restrictive Practices Rules* state that if a state or territory prohibits the use of a restrictive practice, and the registered NDIS provider delivers supports or services to a person with disability in that state or territory:

The registration of the registered NDIS provider is subject to the condition that the provider must not use the restrictive practice in relation to the person with disability.⁶⁹

If the state or territory has an authorisation process for the use of a regulated restrictive practice, the NDIS provider's registration is subject to conditions requiring:⁷⁰

- the use (except a single emergency use) of the practice to be authorised in accordance with the authorisation process
- the provider to lodge with the NDIS Commissioner evidence to that effect as soon as reasonably practicable after the use.

Behaviour support plans

The *NDIS Act* provides that the NDIS Commissioner's 'behaviour support function' includes overseeing the use of restrictive practices by monitoring registered NDIS provider compliance with conditions of registration relating to behaviour support plans.⁷¹ The *NDIS Restrictive Practices Rules* provide that the conditions for a registered NDIS provider include a requirement that a regulated restrictive practice must be used only in accordance with a behaviour support plan.⁷²

Registered NDIS providers are required to report to the NDIS Commission on uses of:⁷³

- unauthorised restrictive practices where use has not been approved by state and territory regulatory frameworks and does not occur in accordance with a behaviour support plan
- authorised restrictive practices where the relevant state or territory authority has approved their use in accordance with a behaviour support plan.

Behaviour support plans, also referred to as a positive behaviour support plans, have been described as:

a document that is intended to identify why the person is displaying the behaviour they are displaying and what they need to do to prevent or minimise that behaviour from occurring. It is also intended to help the people around them to understand the person and why they may be displaying certain behaviours. A positive behaviour support plan should also record the plan or strategies to reduce and ultimately eliminate use of restrictive practices, including through slow and steady implementation of strategies.⁷⁴

Behaviour support plans are prepared by a specialist behaviour support provider. They are reviewed by a specialist behaviour support practitioner at least every year or as soon as practical following a change in circumstances that requires the plan to be amended.⁷⁵ Specialist behaviour support providers are registered NDIS providers who are approved to deliver

specialist behaviour support services to a person with disability.⁷⁶ These services can include conducting functional behaviour support assessments and the development of behaviour support plans.⁷⁷

The *NDIS Restrictive Practices Rules* require a plan to include strategies that are 'evidence-based, person-centred and proactive and that address the person with disability's needs and the functions of the behaviour'.⁷⁸ The plan must also meet all the following requirements:⁷⁹

- clearly identify the regulated restrictive practice to be used
- where the state or territory has a prescribed authorisation process, be authorised according to that process
- ensure the practice is used only as a last resort in response to risk of harm to the person with disability or others, and after the provider has explored and applied evidence-based, person-centred and proactive strategies
- contain the least restrictive response possible in the circumstances to ensure the safety of the person or others
- operate to reduce the risk of harm to the person with disability or others
- be proportional to the potential negative consequence or risk of harm
- ensure the practice is used for the shortest possible time.

In developing a behaviour support plan, the NDIS behaviour support practitioner must undertake a behaviour support assessment including a 'functional behavioural assessment' of the person with disability.⁸⁰ Among other things, the behaviour support practitioner must take all reasonable steps to reduce and eliminate the need for the use of restrictive practices and consult with the person with disability, their family, carers, guardian or other relevant person.⁸¹

The registered NDIS provider must notify a specialist behaviour support provider if there has been a change in circumstances that requires the behaviour support plan to be reviewed.⁸²

Breach of authorisation process or behaviour support plan

Having established a regime where the use of regulated restrictive practices must only be done in accordance with the relevant state or territory authorisation process and in accordance with a behaviour support plan, the *NDIS Restrictive Practices Rules* prescribe actions that must be taken where use of the regulated restrictive practice occurs in breach of the Rules. For this purpose the *NDIS Restrictive Practices Rules* distinguish between an interim support plan and a comprehensive support plan.

Where a registered NDIS provider uses a regulated restrictive practice in accordance with a state or territory authorisation process, but not a behaviour support plan, and use of the restrictive practice is likely to be ongoing,⁸³ the provider must take all reasonable steps to facilitate development of an interim behaviour support plan by a specialist behaviour support

provider within one month of the first use.⁸⁴ They must then take all reasonable steps to facilitate the development of a comprehensive behaviour support plan by a specialist behaviour support provider within six months of the first use.⁸⁵

Where a registered NDIS provider uses a regulated restrictive practice neither authorised by the relevant state or territory process nor in accordance with a behaviour support plan, and use of the restrictive practice is likely to be ongoing,⁸⁶ the NDIS registered provider must obtain authorisation from the state or territory as soon as reasonably practicable and lodge evidence of this with the NDIS Commission.⁸⁷ The NDIS provider must also take all reasonable steps to facilitate the development of an interim behaviour support plan within one month of the first use and a comprehensive behaviour support plan within six months.⁸⁸

Where a regulated restrictive practice does not require authorisation at state or territory level, the *NDIS Restrictive Practices Rules* require its ongoing use to be authorised through a behaviour support plan.⁸⁹ In such cases, the registered NDIS provider must take all reasonable steps to facilitate the development of an interim behaviour support plan within one month of the first use and facilitate the development of a comprehensive behaviour support plan within six months of first use.⁹⁰

Registered NDIS providers are required to comply with the *NDIS Restrictive Practices Rules* as a condition of their registration.⁹¹ Failure to comply with the conditions of registration attracts a civil penalty.⁹²

Authorisation under state and territory law

Each state and territory has a legislative or policy framework which governs the authorisation and use of restrictive practices in disability service settings. The *NDIS Restrictive Practices Rules* operate in conjunction with the laws and policies of the states and territories, but impose specific conditions on registered NDIS providers. The Australian Capital Territory, the Northern Territory, Queensland, South Australia, Tasmania and Victoria have enacted legislation, while New South Wales and Western Australia rely on policies.

Australian Capital Territory

In the Australian Capital Territory, the *Senior Practitioner Act 2018* (ACT) creates the framework for authorising the use of restrictive practices on all adults and children in certain settings. The *Senior Practitioner Act* applies to the same restrictive practices as the *NDIS Restrictive Practices Rules* and to 'verbal directions, or gestural conduct, of a coercive nature'.⁹³

The *Senior Practitioner Act 2018* (ACT) covers a range of 'providers', including 'a person or other entity' who provides disability services to another person.⁹⁴ The Act therefore applies to registered and non-registered NDIS providers.

The *Senior Practitioner Act 2018* (ACT) states that a provider can only use a restrictive practice in accordance with a registered positive behaviour support plan, or where it is 'necessary' to

‘avoid imminent harm to the person or others’.⁹⁵ In the latter case, the provider must report the use of the restrictive practice to the Senior Practitioner within five days after its use.⁹⁶ There is no requirement that a person against whom a restrictive practice is used consents to the use.

The Senior Practitioner is a public servant who is conferred functions and powers under the *Senior Practitioner Act 2018* (ACT) in relation to the reduction, elimination and use of restrictive practices.⁹⁷ The Senior Practitioner does not authorise the use of restrictive practices, but can give advice to disability service providers about the use of restrictive practices under behaviour support plans.⁹⁸ They also provide guidelines on the content, preparation and approval of positive behaviour support plans.

The *Senior Practitioner Act 2018* (ACT) defines a ‘positive behaviour support plan’ as a plan that includes strategies to:⁹⁹

- a. build on the person’s strengths and increase their life skills; and
- b. reduce the intensity, frequency and duration of behaviour that causes harm to the person or others.

A positive behaviour support plan may be prepared by a provider and must be presented to a panel for approval.¹⁰⁰ The panel may only approve a plan where it is:

- consistent with any guidelines made by the Senior Practitioner on how to prepare a positive behaviour support plan¹⁰¹
- it is necessary to prevent harm to the person or others, and is the least restrictive approach reasonably available.¹⁰²

Following approval, the provider may apply to the Senior Practitioner to register the plan.¹⁰³

The provider must regularly review the plan and amend it to reflect any changes in circumstances.¹⁰⁴ The plan expires 12 months after it is registered.¹⁰⁵

The person with disability (or any other person whose interests are affected) can apply to the Australian Capital Territory Civil and Administrative Tribunal (ACAT) for review of the Senior Practitioner’s decision to register a positive behaviour support plan that includes the authorised use of restrictive practices. ACAT can also review decisions of the Senior Practitioner regarding a refusal to register a positive behaviour support plan, cancellation of a positive behaviour support plan, refusal to register a positive behaviour support panel or a direction given to a provider.¹⁰⁶

The *Senior Practitioner Act 2018* (ACT) makes it an offence to use a restrictive practice other than in accordance with a registered positive behaviour support plan, except where the provider reasonably believes it necessary to prevent serious and imminent injury or illness to any person.¹⁰⁷ A service provider is guilty of an offence if it fails to comply with a direction from the Senior Practitioner.¹⁰⁸ The maximum penalty for either offence is 50 penalty units and/or imprisonment for 6 months.¹⁰⁹

New South Wales

In New South Wales, the authorisation and use of restrictive practices is governed by the Restrictive Practices Authorisation Policy (NSW Policy). The NSW Policy covers the same restrictive practices as in the *NDIS Restrictive Practices Rules*.¹¹⁰

The NSW Policy applies to all registered NDIS providers and behaviour support practitioners operating in New South Wales who provide supports to children and adults who are NDIS participants.¹¹¹ It does not apply to people with disability receiving disability services from other non-registered providers.

The NSW Policy sets out an authorisation process for the use of restrictive practices that requires:

- development of a behaviour support plan in accordance with the *NDIS Restrictive Practices Rules*
- informed consent by or on behalf of the person with disability, either:
 - by the participant providing their consent
 - where an adult participant does not have capacity to consent, a guardian with the authority for restrictive practices matters providing their consent
 - in the case of a child, consent by a parent or guardian¹¹²
- approval from the Restrictive Practices Authorisation Panel (RPA Panel)¹¹³
- each registered NDIS provider must have a panel that authorises and reviews restrictive practices. The RPA Panel is to consist of at least a senior manager employed by the provider, and a specialist with expertise in behaviour support who is independent of the service provider.¹¹⁴

An authorisation granted by the RPA Panel lasts up to 12 months.¹¹⁵

The NSW Policy creates an exception to the above process in emergencies where there is a clear and immediate risk of harm.¹¹⁶ In those cases, the provider must take reasonable steps to facilitate the development of an interim behaviour support plan that covers the practice within one month of the first use, and seek interim authorisation from a senior manager of the provider as soon as possible.¹¹⁷ The senior manager will ordinarily be on the RPA Panel.¹¹⁸

RPA Panel decisions are not subject to review, other than by way of a complaint to the Panel.

Any unauthorised use of restricted practices is regarded as a 'reportable incident',¹¹⁹ and must be reported to the NDIS Commissioner within five business days.¹²⁰

In January 2021, the New South Wales Government published an exposure draft of the Persons with Disability (Regulation of Restrictive Practices) Bill 2021 (NSW). The Bill would codify regulation of restrictive practices by NDIS registered providers, adopting the broader definition

of 'restrictive practices' in the *NDIS Act*.¹²¹ The Ageing and Disability Commissioner would have the function of reviewing decisions by authorisation panels to approve the use of restrictive practices against NDIS participants.¹²² An authorisation panel would consist of the registered NDIS provider proposing to use the restrictive practice and an independent NDIS behaviour support practitioner.¹²³

The draft was prepared following a public consultation process held in 2019.¹²⁴ The Bill had not been introduced into New South Wales Parliament at the time this *Final report* was completed. It is not clear if the Bill in its current form will be progressed and, if so, when.

Northern Territory

The use of restrictive practices in relation to adult and child NDIS participants is regulated by the *National Disability Insurance Scheme (Authorisations) Act 2019* (NT) (*Authorisations Act*). The *Authorisations Act* adopts the definition given to each type of regulated restrictive practice under the *NDIS Restrictive Practices Rules*.¹²⁵

It establishes overarching principles which emphasise that services must be provided in a way that aims to reduce or eliminate the use restrictive practices, uses them as a last resort, only in accordance with a behaviour support plan and in the least restrictive way possible.¹²⁶

If a registered NDIS provider seeks to use a restrictive practice on a participant, the provider must develop a behaviour support plan or interim behaviour support plan for the participant that meets the requirements of the *NDIS Restrictive Practices Rules*.¹²⁷ The NDIS provider must apply to the Senior Practitioner (a public servant appointed by the Minister) for authorisation or interim authorisation.¹²⁸ An application to the Senior Practitioner must contain, among other things, a copy of the behaviour support plan and evidence of consultation with the participant and with their family, carers, or guardian about the proposed use of the restrictive practice.¹²⁹

The Senior Practitioner may grant an authorisation or interim authorisation if:¹³⁰

- the behaviour support plan is consistent with the Senior Practitioner's guidelines and the principles of the *Authorisations Act*
- the restrictive practice is necessary to prevent harm to the participant or others, and is the least restrictive approach reasonably available.

The Senior Practitioner may also refuse to grant the authorisation, propose an amendment to the behaviour support plan or propose an alternative restrictive practice.¹³¹ The Senior Practitioner may revoke authorisation at any time.¹³² An affected person may seek internal and tribunal review of the Senior Practitioner's decision to authorise, refuse authorisation of, or revoke authorisation for, a restrictive practice.¹³³

The person with disability or their guardian, the NDIS provider, or the NDIS behaviour support practitioner are able to apply to the CEO of the Northern Territory Department of Health for an internal review of a decision to authorise the use of restrictive practices.¹³⁴ The CEO may affirm,

vary or set aside the decision and substitute a new decision.¹³⁵ An application may be made to the Northern Territory Civil and Administrative Tribunal to review the CEO's decision.¹³⁶

The *Disability Services Act 1993* (NT) regulates the use of 'restrictive interventions' in the context of residential facilities, which most often accommodate people with disability subject to treatment or supervision orders. The Act defines a restrictive intervention as 'any intervention used to restrict the resident's rights or freedom of movement at the facility', including chemical restraint, physical restraint, seclusion and restricting access.¹³⁷

Before a person with a disability becomes a resident of a secure care facility, the CEO must prepare a behaviour support plan for the person stating a range of strategies to be used in managing the person's behaviour.¹³⁸ If the behaviour support plan includes restrictive interventions, it must show how it is 'the option that is the least restrictive of the person as is possible in the circumstances'.¹³⁹ The inclusion of restrictive interventions is subject to review by a review panel.¹⁴⁰

The *Disability Services Act 1993* (NT) makes it an offence to use a restrictive intervention on a resident of a residential facility, unless:¹⁴¹

- the use is necessary to prevent the resident from causing physical harm to himself or herself or others, or to prevent the resident from destroying property if to do so could involve the risk of harm to himself or herself or others
- the use and form of the restrictive intervention is the option that is the least restrictive of the resident as is possible in the circumstances
- the use and form of the restrictive intervention is in accordance with the resident's behaviour support plan.

Queensland

The *Disability Services Act 2006* (Qld) defines 'restrictive practices' as any of the following actions used to respond to the behaviour of an adult with an intellectual or cognitive disability that causes harm to themselves or others:¹⁴²

- containing or secluding the adult
- using chemical, mechanical or physical restraint on the adult
- restricting access of the adult.

Each of these restrictive practices is individually defined in the *Disability Services Act 2006* (Qld) in ways that are similar to the preceding jurisdictions and the *NDIS Restrictive Practices Rules*.¹⁴³

Part 6 of the *Disability Services Act 2006* (Qld) regulates the use of restrictive practices by 'relevant service providers' that provide disability services, or NDIS supports or services to an adult with an intellectual or cognitive disability.¹⁴⁴ The *Disability Services Act 2006* (Qld) specifies the circumstances in which a relevant service provider is authorised to use a restrictive

practice.¹⁴⁵ The Act imposes different conditions on the authorisation and use of a restrictive practice, depending on the type of restrictive practice being used and the specific type of disability service setting in which authorisation for use is sought. Generally, it authorises the use of a restrictive practice where:

- the adult has been assessed by an appropriately qualified person¹⁴⁶
- a behaviour support plan has been prepared for the adult by the service provider¹⁴⁷
- consent to use the restrictive practice has been given by a guardian or informal decision-maker or, for containment and seclusion, the Queensland Civil and Administrative Tribunal (QCAT).¹⁴⁸

The *Disability Services Act 2006* (Qld) provides in relation to multiple types of restrictive practices that the consent of the adult with cognitive or intellectual disability is not required.¹⁴⁹

In all cases, use of the restrictive practice must:¹⁵⁰

- be necessary to prevent the adult's behaviour causing harm to the adult or others
- be the least restrictive way of ensuring the safety of the adult or others
- comply with the positive behaviour support plan for the adult.

A service provider can obtain short-term approval for an exemption from these requirements for six months.¹⁵¹

The *Disability Services Act 2006* (Qld) provides for internal review of decisions of the chief executive of the Department of Seniors, Disability Services and Aboriginal and Torres Strait Islander Partnerships related to restrictive practices, including a decision not to develop a behaviour support plan providing for the use of a restrictive practice.¹⁵² The *Guardianship and Administration Act 2000* (Qld) provides that QCAT can review other decisions, such as the grant of a containment or seclusion approval.¹⁵³ QCAT can also review decisions made by a guardian about restrictive practices.¹⁵⁴

Service providers are subject to certain reporting obligations regarding their use of restrictive practices, and must provide specified information to concerned parties (such as the person subject to the practice, or their guardian).¹⁵⁵ Without proper authorisation, the use of a restrictive practice may be an offence.¹⁵⁶

The Queensland Government is currently undertaking a review to determine how the Queensland regime governing the use of restrictive practices could 'better align' with the NDIS Framework and the Draft Principles for Consistent Authorisation.¹⁵⁷ The consultation process for this review concluded on 31 January 2022. The consultation paper for the review, *Reforming Queensland's authorisation framework for the use of restrictive practices in NDIS and particular disability service settings*, canvassed reform options including:

- a more streamlined authorisation framework moving away from a model where guardians authorise the use of restrictive practices and introducing a Senior Practitioner¹⁵⁸ to authorise the use of restrictive practices and report and publish data on its functions¹⁵⁹
- a revised review function for QCAT, including review of decisions made by a Senior Practitioner¹⁶⁰
- facilitating greater participation of people with disability in the authorisation and use of restrictive practices.¹⁶¹

South Australia

In South Australia, authorisation and use of restrictive practices in disability services is regulated by the *Disability Inclusion Act 2002* (SA) and the *Disability Inclusion (Restrictive Practices—NDIS) Regulations 2021* (SA) (*Disability Inclusion Regulations*). Both instruments are limited to use of restrictive practices by a registered or unregistered NDIS provider¹⁶² on an NDIS participant or person who receives NDIS supports.¹⁶³ This includes both adults and children.¹⁶⁴

The *Disability Inclusion Act 2002* (SA) defines restrictive practices by reference to the definitions in the *NDIS Restrictive Practices Rules*.¹⁶⁵ It also sets out principles which are to be observed in the use of restrictive practices. These include that the use of restrictive practices must be done in a manner that is, as far as is practicable, consistent with the person's human rights.¹⁶⁶ The use of restrictive practices must also be done in compliance with any restrictive practices guidelines published by the relevant minister.¹⁶⁷

The *Disability Inclusion Regulations* distinguish between 'Level 1 restrictive practices', which include environmental, mechanical and chemical restraints, and 'Level 2 restrictive practices' which include seclusion and certain kinds of environmental, mechanical and chemical restraints.¹⁶⁸ The latter include the administration of a drug via an 'invasive procedure', the use of two or more psychotropic drugs, or hormonal manipulation.¹⁶⁹ The *Disability Inclusion Regulations* also prohibit certain types of restrictive practices, including prone restraint, supine restraint, any restraint intended to restrict or affect respiratory or digestive function, forcing a person's head down to their chest, and restrictive practices that involve or include deliberate infliction of pain to secure compliance.¹⁷⁰

The Senior Authorising Officer (SAO) can authorise 'level 1' and 'level 2' restrictive practices on prescribed persons if they believe on reasonable grounds that:¹⁷¹

- the prescribed person is displaying behaviour that constitutes a risk of harm; and
- the use of level 1 or 2 restrictive practices is necessary to minimise the risk of harm, or to prevent further harm from being caused; and
- the prescribed person has a behaviour support plan; and
- the behaviour support plan was prepared in consultation with the prescribed person; and
- the use of level 1 or 2 restrictive practices of the relevant kind is contemplated by, and consistent with, the prescribed person's behaviour support plan.

The SAO is a public servant appointed to that role by the Minister and is responsible for advising the Minister about the use of restrictive practices, assisting the Minister in preparing restrictive practice guidelines, providing education and training about restrictive practices, and other functions.¹⁷²

The SAO may also authorise an employee of a registered NDIS provider to be an Authorised Program Officer (APO).¹⁷³ Upon becoming an APO, the person will be empowered to directly authorise use of level 1 restrictive practices.¹⁷⁴

A registered NDIS provider may only use restrictive practices (whether authorised by the SAO or an APO) if there is no other way to minimise the risk of harm, or to prevent further harm from being caused, that is reasonably available in the circumstances.¹⁷⁵ Restrictive practices may be used without the consent of the person and despite their refusal to consent to their use.¹⁷⁶ However, the *Disability Inclusion Act 2002* (SA) expressly provides that restrictive practices may not be used as a form of punishment, for the convenience of others, or to address inadequate staffing, equipment or facilities.¹⁷⁷

A person who is aggrieved by a decision of an APO or an NDIS provider regarding the authorisation of restrictive practices is entitled to a review of the decision by the SAO. The SAO may confirm, vary, or reverse the decision under review.¹⁷⁸

The person with disability, their family members, guardian, nominated advocate or NDIS provider may apply to the South Australian Civil and Administrative Tribunal to review a decision of the SAO regarding the decision to authorise the use of restrictive practices.¹⁷⁹

A disability service provider will not incur civil or criminal liability for an act or omission relating to the use of restrictive practices in accordance with the *Disability Inclusion Act 2002* (SA), if the act or omission was made in good faith and without negligence.¹⁸⁰

Tasmania

The *Disability Services Act 2011* (Tas) regulates the use of ‘restrictive interventions’. These are defined as:

any action that is taken to restrict the rights or freedom of movement of a person with disability for the primary purpose of the behavioural control of the person but does not include such an action that is –

(a) taken for therapeutic purposes; or

(b) taken to enable the safe transportation of the person; or

(c) authorised under any enactment relating to the provision of mental health services or to guardianship.¹⁸¹

The Act also distinguishes between ‘environmental restriction’ and ‘personal restriction’. The former is the ‘modification of an object, or the environment of the person, so as to enable the behavioural control of the person but does not include a personal restriction’.¹⁸² The latter is a ‘restrictive intervention in relation to the person that consists wholly or partially of physical contact with the person so as to enable the behavioural control of the person, or the taking of an action that restricts the liberty of movement of the person’.¹⁸³

The *Disability Services Act 2011* (Tas) applies to ‘disability services providers’, defined as ‘a person or organisation that provides ... specialist disability services’, other than a relative or friend of the person with disability or a prescribed body.¹⁸⁴ This means it applies to both registered NDIS providers and non-registered providers in relation to all persons with disability.¹⁸⁵

The Act states that a disability service provider must not use a restrictive intervention in relation to a person with disability unless the intervention:

- is carried out in accordance with a relevant approval given by the Secretary (for environmental restrictions)¹⁸⁶ or Tasmanian Civil and Administrative Tribunal (for environmental and personal restrictions),¹⁸⁷ and
- does not contravene any direction given by the Secretary of the Department of Social Services or Board,¹⁸⁸ or
- the restrictive intervention is covered by a ‘relevant authorisation’ (which relates to authorisations given under the *Mental Health Act 2013* (Tas) and similar legislation permitting what would otherwise be restrictive interventions).¹⁸⁹

It is an offence to use a restrictive intervention other than in accordance with these conditions.¹⁹⁰ A number of defences are available to this offence, including where the intervention was necessary to protect the person with disability or another person from serious harm.¹⁹¹

The *Disability Services Act 2011* (Tas) provides for a Senior Practitioner who has functions including monitoring and evaluating the use of restrictive interventions and developing best practice standards and guidelines.¹⁹² If the Senior Practitioner believes on reasonable grounds that a type of restrictive intervention is being used by a provider or funded person in breach of the Act, they may investigate the situation.¹⁹³

The *Disability Services Act 2011* (Tas) is currently under review by the Tasmanian Department of Communities.¹⁹⁴ The object of the review is to align the Act with the *NDIS Restrictive Practices Rules*.¹⁹⁵ The review process has included community consultations held between October 2021 and March 2022, but the Department of Communities has not indicated when the review will be completed.¹⁹⁶

Victoria

The *Disability Act 2006* (Vic) governs the authorisation and use of regulated restrictive practices in disability services, meaning services ‘specifically for the support of persons with disability which is provided by a disability service provider’.¹⁹⁷ ‘Disability service provider’ means the Secretary of the Department of Families, Fairness and Housing, or a person or body ‘on the register of disability service providers’, which is not limited to registered NDIS providers.¹⁹⁸

The *Disability Act 2006* (Vic) regulates the use of restrictive practices against adult and child NDIS participants, as well as any person receiving supports under the Commonwealth Disability Support for Older Australians Program (DSOA), within the context of disability services.¹⁹⁹

The Act defines ‘restrictive practice’ as ‘any practice or intervention that has the effect of restricting the rights or freedom of movement of a person with a disability or of an NDIS participant or a DSOA client’.²⁰⁰ It also adopts the same definitions of mechanical restraint, physical restraint and seclusion as in the *NDIS Restrictive Practices Rules*.²⁰¹

Part 7 of the *Disability Act 2006* (Vic) provides that a disability service provider must not use a restrictive practice on an NDIS participant unless:

- other than in emergencies, use of the restrictive practice has been authorised by the service provider’s APO.²⁰² Generally speaking, an APO may authorise the use of a restrictive practice if satisfied that it is necessary, the least restrictive option and to be used in accordance with the participant’s behaviour support plan.²⁰³
- if the practice is seclusion, physical restraint or mechanical restraint, it has been approved by the Senior Practitioner²⁰⁴
- the proposed use of the practice is necessary to prevent the person causing physical harm to themselves or another person.²⁰⁵

In Victoria, an APO is an employee of a disability service provider or a registered NDIS service provider appointed to the position by the service provider, subject to approval by the Senior Practitioner.²⁰⁶ The Senior Practitioner is appointed to perform specific regulatory functions relating to the use, reduction and elimination of restrictive practices.²⁰⁷ The APO is responsible for ensuring restrictive practices used in disability services are compliant with the *Disability Act 2006* (Vic).²⁰⁸

The APO must ensure an ‘independent person’ is available to explain the proposed use of restrictive practices to the NDIS participant, and advise that they may seek a review of the decision to authorise the use of restrictive practices.²⁰⁹

If the independent person considers the NDIS participant is not able to understand the proposed use of the restrictive practice and the requirements of the authorisation process are not being complied with, the independent person may report the matter to the Public Advocate or the Senior Practitioner.²¹⁰ After receiving a report, the Public Advocate may refer the matter to the Senior Practitioner, initiate an application to the Victorian Civil and Administrative Review Tribunal (VCAT), and disclose information to the NDIA or the NDIS Commission regarding the use or proposed use of restrictive practices.²¹¹

An NDIS participant may apply to VCAT for a substantive review of a decision to authorise the use of a restrictive practice (whether this was approved by an APO or the Senior Practitioner). VCAT may confirm the decision to authorise the use of restrictive practices, order the NDIS provider to request a review of the behaviour support plan, or direct that the restrictive practices not be used. An NDIS provider can also apply to VCAT for a review of a decision not to authorise the use of restrictive practices.²¹²

Western Australia

The use of restrictive practices in Western Australia is governed by the Authorisation of Restrictive Practices in Funded Disability Services Policy (Restrictive Practices Policy).²¹³ The Restrictive Practices Policy was to operate until 1 July 2023, at which time legislation was expected to be introduced which will align with the Draft Principles for Nationally Consistent Authorisation.²¹⁴ At the time of writing, the community consultation process was still ongoing and no draft bill had been made available.

The Restrictive Practices Policy applies to the same restrictive practices that are regulated by the *NDIS Restrictive Practices Rules* and applies to all people with disability.²¹⁵ Similar to South Australia, the Restrictive Practices Policy prohibits the use of certain 'restrictive practices' including prone restraint, supine restraint, 'pin downs', 'basket holds' and 'takedown techniques'. It also prohibits any physical restraints used for 'the purpose or effect of restraining or inhibiting a person's respiratory or digestive functioning', or '[having] the effect of pushing the person's head forward onto their chest', or having the purpose or effect of compelling compliance through infliction of pain.²¹⁶

The Restrictive Practices Policy does not distinguish between adults and children with disability. While it applies to 'any service provider that is funded through the NDIS or by the Western Australian Government Department of Communities to deliver disability services to a person with disability', the Policy supplements the requirements set by the *NDIS Restrictive Practices Rules* by establishing an authorisation process.²¹⁷ Authorisation must be obtained by a provider prior to using a restrictive practice on a person with disability.²¹⁸ In order to obtain authorisation, a registered NDIS provider must develop a behaviour support plan that outlines the proposed use of the restrictive practice.²¹⁹ The provider must then submit the behaviour support plan to a Quality Assurance Panel.²²⁰

The Quality Assurance Panel conducts an independent review of the proposed restrictive practice(s) and, where appropriate, makes recommendations on how the behaviour support plan can be improved.²²¹ The Panel is associated with each registered NDIS provider and consists of at least two members: a senior manager employed by the provider and an NDIS Behaviour Support Practitioner who is not employed by the provider.²²²

Where a restrictive practice is used without authorisation under the Restrictive Practices Policy, the service provider must comply with reporting requirements either to the NDIS Commission (in the case of NDIS services), or to the Department of Communities (for state funded services).²²³

Health and mental health settings

All states and territories other than New South Wales have legislation regulating the use of restrictive practices in mental health settings. Legislation typically refers to persons or patients requiring or receiving treatment and care, including involuntary care, rather than people with disability. The legislation in place around Australia is supported by various policies, guidelines, standards or handbooks.²²⁴ Similar to requirements in disability settings, there is usually some kind of authorisation process before a restrictive practice can be used in mental health settings, although these vary significantly across jurisdictions.

The Australian Commission on Safety and Quality in Healthcare (ACSQHC) has standards to improve the quality of health care in Australia.²²⁵ The Explanatory Notes to the standards state:

Minimising and, where possible, eliminating the use of restrictive practices (including restraint and seclusion) are key parts of national mental health policy. Minimising the use of restraint in other healthcare settings besides mental health has also been identified as a clinical priority.²²⁶

Action 5.35 in the standards is called 'Minimising restrictive practices: restraint' and aims to reduce the use of restraint in all Australian health settings.²²⁷ The ACSQHC notes that 'outside of mental health services, restraint is used, but often with less reporting and oversight'. It also states that 'older people with cognitive impairment are more likely than the general population to be restrained in acute care services, and also more likely to experience adverse outcomes relating to the use of restraint'.²²⁸

In 2016, the Australian Health Ministers' Advisory Council agreed to National Principles to Support the Goal of Eliminating Mechanical and Physical Restraint in Mental Health Services.²²⁹ While not legally binding, the Principles recognise restrictive practices are 'a last resort' and the dignity and rights of people accessing mental health services should be respected and supported at all times.²³⁰

Though expressed using different language, regulatory regimes in the majority of states and territories provide that restrictive practices must be used as a last resort, only after other strategies have been tried or considered, as the least restrictive response and for the shortest time possible.²³¹

Most jurisdictions also have laws or policies regulating the use of restrictive practices in general health settings, including transportation by ambulance. These are generally less detailed than the equivalent regimes governing mental health settings.

Australian Capital Territory

Mental health

The *Mental Health Act 2015* (ACT) regulates the use of particular practices, including detention, confinement, involuntary seclusion, restraint, and forcible giving of medication with respect to people subject to particular provisions of the Act, although it does not describe those actions as restrictive practices. The Act applies to both adults and children.²³²

Those practices may be used on a person subject to an assessment order, psychiatric treatment order, community care order and restriction order, an order for assessment for emergency detention, authorisation for involuntary detention, treatment or care, forensic psychiatric treatment orders and forensic community care orders.²³³

Legislation confers decision-making power with respect to the detention, seclusion or restraint, forcible administration of medication on the Chief Psychiatrist for psychiatric treatment orders and the care coordinator for community care orders.²³⁴ Where a person is subject to an involuntary detention order, the person with decision-making power is ‘the person in charge of the facility’ where the person is detained.²³⁵

In all cases, the decision-maker can subject the person to the minimum confinement and restraint necessary and reasonable to prevent the person from causing harm to themselves or someone else, or ensure the person remains in custody under the order.²³⁶ Similarly, the person may be subject to involuntary seclusion if the relevant decision-maker is satisfied that it is the only way in the circumstances to prevent the person from causing harm to themselves or someone else.²³⁷

Where the decision-maker subjects a person to restraint, involuntary seclusion or forcible giving of medication, the decision-maker must:

- (a) enter in the person’s record the fact of and the reasons for the restraint, involuntary seclusion or forcible giving of medication; and
- (b) tell the public advocate in writing of the restraint, involuntary seclusion or forcible giving of medication; and
- (c) keep a register of the restraint, involuntary seclusion or forcible giving of medication.²³⁸

The *Mental Health (Secure Facilities) Act 2016* (ACT) also allows the use of force by authorised health practitioners against patients of a secure mental health facility in limited circumstances, and only as a last resort.²³⁹ In those circumstances, force may only be used if the authorised health practitioner:

- (a) gives a clear warning of the intended use of force; and
- (b) allows enough time for the warning to be observed; and

-
- (c) uses no more force than is necessary and reasonable in the circumstances; and
 - (d) uses force, as far as practicable, in a way that reduces the risk of causing death or grievous bodily harm.²⁴⁰

These requirements need not be complied with 'in urgent circumstances' where the practitioner believes on reasonable grounds that compliance would create a risk of injury to the practitioner, the patient or anyone else.²⁴¹ The patient must be examined as soon as practicable and given appropriate health care following the use of force.²⁴²

General health

The 'Restraint of a Person: Adults Only' policy applies to all staff of ACT Health. It covers 'physical restraint, mechanical restraint and the forcible giving of medication for essential clinical care'. It does not cover detention, confinement or seclusion.²⁴³

The policy states that the use of restraint on a person who is not being treated under the *Mental Health Act 2015* (ACT) is governed by common law, the *Crimes Act 1900* (ACT), *Powers of Attorney Act 2006* (ACT) and *Guardianship and Management of Property Act 1991* (ACT).²⁴⁴ People being treated other than under the *Mental Health Act 2015* (ACT) must not be restrained unless either:²⁴⁵

- the person consents
- if the person does not have capacity to consent, a substitute decision-maker has statutory authority to give consent and provides it
- a defence of necessity for the use of restraint applies to preserve life or human safety.

The policy sets out processes for:

- assessment of a person prior to restraint, requiring staff to identify the behaviour of concern and undertake a comprehensive assessment²⁴⁶
- requirements for the application of physical restraint, mechanical restraint and the forcible giving of medication, noting these:²⁴⁷
 - are 'only permitted as a last resort, when all other reasonable efforts at meeting the person's clinical need without restraint have been unsuccessful'
 - 'must be proportionate to the risks being averted and must consider the least intrusive and invasive, and most dignified' approach
- monitoring and care of the person during restraint²⁴⁸
- communication with the person and their next of kin, substitute decision-maker or nominated person²⁴⁹
- care of the person post restraint.²⁵⁰

New South Wales

Mental and general health

In New South Wales, the Seclusion and Restraint in NSW Health Settings Policy Directive (NSW Policy Directive) regulates the use of seclusion and restraint (including physical, mechanical and chemical restraint) against adults and children in all NSW Health settings, including general health, ambulance and mental health settings.²⁵¹

Under the NSW Policy Directive, chemical restraint is defined as ‘the use of medication or chemical substance for the primary purpose of restricting a person’s movement’ and is distinguished from acute sedation that is used to allow continuation of an assessment or treatment.²⁵² Mechanical restraint is defined as ‘application of devices to a person’s body to restrict their movement’ and is only to be authorised or used by designated, authorised and trained staff.²⁵³ Physical restraint is defined as the use of “hands-on” immobilisation or the physical restriction of a person to prevent them from harming themselves or endangering others, or to ensure that essential medical treatment can be provided’.²⁵⁴ Seclusion is defined as ‘confinement of a person, at any time ... alone in a room or area from which free exit is prevented’. The purpose, duration or location of seclusion is not relevant in determining whether an act is seclusion.²⁵⁵

The NSW Policy Directive provides that there must be ‘a lawful purpose to restrain any person or to use seclusion’.²⁵⁶ It provides that health staff must not:²⁵⁷

- use seclusion and restraint as a form of discipline, punishment or threat
- use seclusion for people who are actively self-harming or suicidal
- use seclusion or restraint as a means to reduce behaviours not associated with immediate risk of harm
- seclude a person who is also being mechanically restrained
- use metal handcuffs or hard manacles as a form of mechanical restraint (although a person may be in metal handcuffs when they have been transported by police or other custodial staff and remain under police or other custodial supervision while in the health facility)
- use vest restraints for older people.

The NSW Policy Directive provides that in all cases use of seclusion and restraint should be ‘a last resort’, applied using no more force than is reasonable and proportionate in the circumstances and necessary to deal with the risk of harm, and after less restrictive alternatives have been trialled or considered.²⁵⁸ The use of seclusion or restraint should end as soon as the reason for the intervention has ended ‘and it is safe to do so’.²⁵⁹ The NSW Policy Directive states that particular attention must be given to people with disability in decisions relating to seclusion or restraint.²⁶⁰

The NSW Policy Directive states that seclusion and restraint are ‘often initiated at short notice, in response to an emergency situation’.²⁶¹ Accordingly, the NSW Policy Directive does not

require authorisation prior to the use of seclusion and restraint in every case, but instead requires that use be ‘ratified by a senior clinician as soon as possible, but no more than one hour after the practice was initiated’, after which the practice must cease or may be allowed to continue.²⁶² A senior clinician must also review the person subjected to the practice ‘as frequently as possible but not less than every four hours, until the intervention is ceased’.²⁶³ Where seclusion or ‘four-limb mechanical restraint’ is used, NSW Health clinical staff must continuously observe, and where possible, engage with the person for the duration of the practice.²⁶⁴ For other forms of restraint, the person must be continuously observed for the first hour, then at least every 15 minutes.²⁶⁵

NSW Health staff must document all incidences of seclusion and restraint and debriefing sessions in the Health Care Record to enable a review of such practices.²⁶⁶ The NSW Policy Directive requires records to include the person’s ‘Aboriginal identification’, but does not refer to disability.²⁶⁷ There are additional reporting requirements in declared emergency departments and in mental health units, but these also do not refer to people with disability.²⁶⁸ In the case of NSW Ambulance settings, the NSW Policy Directive states that where a person meets the criteria for being mentally ill or mentally disturbed and is being detained, staff must complete a form under section 20 of the *Mental Health Act 2007* (NSW) each time restraint is used.²⁶⁹

There are no other separate pieces of legislation or publicly available policies which address restrictive practices in mental health settings specifically. The use of restrictive practices in mental health settings is not otherwise addressed in the *Mental Health Act 2007* (NSW).

Northern Territory

Mental health

The use of mechanical restraint and seclusion in mental health settings is governed by the *Mental Health and Related Services Act 1998* (NT). Mechanical restraint is defined under the Act as:

the application of a device (including a belt, harness, manacle, sheet and strap) on a patient’s body to restrict the patient’s movement, but does not include the use of furniture (including a bed with sides and a chair with a table fitted on its arms) that restricts the patient’s capacity to get off the furniture.²⁷⁰

Seclusion is defined as ‘confinement of the patient at any time of the day or night alone in a room or area from which free exit is prevented’.²⁷¹

Neither mechanical restraints nor seclusion may be used on a person admitted as a voluntary patient for longer than six continuous hours, so these practices principally are applied to involuntary patients.²⁷²

The Act provides that mechanical restraint or seclusion can only be used on a patient where it has been approved by an authorised psychiatric practitioner or, in emergencies, by the senior

registered nurse on duty.²⁷³ There must also be no other, less restrictive method of control and the restraint must be necessary for one or more of the following reasons:²⁷⁴

- medical treatment of the patient
- to prevent the patient from injuring themselves or another person
- to prevent the patient from persistently destroying property
- to prevent the patient from absconding from the facility.

A patient subjected to seclusion or mechanical restraint must be kept under regular observation and review, and given access to certain essentials.²⁷⁵

The use of the seclusion or mechanical restraint, the details of, and reasons for its use must be recorded by the person in charge of an approved treatment facility in a place inspected by a community visitor,²⁷⁶ recorded in the patient's medical file²⁷⁷ and communicated to the patient's adult guardian or decision maker (if the patient has one).²⁷⁸

The *Mental Health and Related Services Act 1998* (NT) imposes a maximum penalty of 40 penalty units where seclusion or mechanical restraint are used in breach of the provisions of the Act.²⁷⁹

General health

Beyond mental health settings, all services within NT Health are required to comply with the requirements of the NT Health Seclusion and Restraint Policy, which is located on the staff intranet but does not appear to be publicly available.²⁸⁰

Queensland

Mental health

Chapter 8 of the *Mental Health Act 2016* (Qld) regulates the use of mechanical restraint, seclusion and physical restraint on patients in authorised mental health services.²⁸¹ It is not limited to people with disability. Generally, seclusion and mechanical restraint must only be used where approved by an appropriate medical practitioner or the chief psychiatrist.²⁸² Use of restraint must involve no more force than reasonably necessary, and use of either restraint or seclusion is subject to time limits and monitoring obligations.²⁸³

The *Mental Health Act 2016* (Qld) also allows the administration of medication to a person or the use of a mechanical restraint on an involuntary patient but only for the purpose of transporting those persons.²⁸⁴

The chief psychiatrist's approval of the use of a mechanical restraint or seclusion may include a reduction and elimination plan.²⁸⁵ A plan is developed by an authorised doctor and provides for

the elimination or reduction of either practice or both.²⁸⁶ It must contain information about any previous use of the restraint or seclusion, any strategies previously used to reduce use of these practices and information about the strategies the doctor proposes to reduce and eliminate use of the practice in the future.²⁸⁷

Physical restraint, being use by a person of their body to restrict a patient's movement,²⁸⁸ may also be used in limited circumstances. Physical restraint may be authorised by an authorised doctor or the health practitioner in charge of an inpatient or other specified unit only where there is no other reasonably practicable way to protect the patient or others from harm, provide treatment and care to the patient, prevent serious damage to property, or prevent an involuntary patient from leaving an authorised mental health service.²⁸⁹ The health practitioner in charge of an inpatient unit must record the required information about the use of the mechanical restraint or seclusion on the patient.²⁹⁰

The chief psychiatrist is required to make policies on the use of physical restraint, mechanical restraint and seclusion.²⁹¹ Policies of relating to all three types of restrictive practices have been published and contain guidance relating to recording the use of each practice.²⁹² Each provides the type of information that must be contained in the report, and require the chief psychiatrist to be immediately notified of the death of a patient during or within 24 hours of the patient being subjected to physical or mechanical restraint or seclusion, or if the patient or some other person experiences significant harm.²⁹³

The *Mental Health Act 2016* (Qld) creates an offence where a person uses a mechanical restraint, seclusion or physical restraint in ways other than in compliance with the Act. The maximum penalty is 200 penalty units.²⁹⁴

General health

No specific legislation governs the use of restrictive practices in general health settings in Queensland. However, the *Public Health Act 2005* (Qld) states that an ambulance officer or police officer may detain a person and transport the person to a treatment or care place if they believe:²⁹⁵

- a person's behaviour, including, for example, the way in which the person is communicating, indicates the person is at immediate risk of serious harm
- the risk appears to be the result of a major disturbance in the person's mental capacity, whether caused by illness, disability, injury, intoxication or another reason
- the person appears to require urgent examination, or treatment and care, for the disturbance.

If the treatment or care place is a public sector health service facility (other than an 'inpatient hospital'), the person may only be transported to the facility with the approval of the person in charge of the facility.²⁹⁶

South Australia

Mental health

The *Mental Health Act 2009* (SA) governs the use of restrictive practices against patients in mental health settings in South Australia. It defines those practices as ‘the use of physical, mechanical or chemical means to restrain a patient’ and ‘seclusion or the confinement of the patient on [their] own in an area from which [they] cannot leave of [their] own volition’.²⁹⁷

The Act’s guiding principles provide that ‘mental health services should be provided on a voluntary basis as far as possible, and otherwise in the least restrictive way and in the least restrictive environment that is consistent with their efficacy and public safety’.²⁹⁸ The principles specifically provide that ‘restrictive practices should be used only as a last resort for safety reasons and not as a punishment or for the convenience of others’.²⁹⁹ The Act also creates the position of Chief Psychiatrist, whose functions include monitoring the use of restrictive practices on voluntary and involuntary patients.³⁰⁰

In addition, the Chief Psychiatrist’s Restraint and Seclusion Standard applies to all those involved in the administration and operation of the *Mental Health Act 2009* (SA) across public and private settings.³⁰¹ It describes expectations on the use of restraint and seclusion in health services where a patient with mental illness may be assessed and treated in a health setting under *Mental Health Act 2009* (SA) powers, including an ambulance, hospital or community mental health services.³⁰²

Under the *Mental Health Act 2009* (SA), treatment centre staff may take measures for the confinement of a patient, and restrain the patient or otherwise use force, as reasonably required in the circumstances.³⁰³

- for carrying an inpatient treatment order applying to the patient into effect and ensuring compliance with the Act
- for maintaining order and security at the centre or the prevention of harm or nuisance to others.

The *Mental Health Act 2009* (SA) does not regulate the use of chemical restraints. However, the Chief Psychiatrist’s Restraint and Seclusion Standard states that chemical restraints may be initiated by practitioners who have the authority to prescribe controlled substances, including paramedics, nurse practitioners and medical practitioners.³⁰⁴ The Restraint and Seclusion Standard prohibits the use of drugs or higher doses of medication that create continuous sedation for the purposes of managing behaviour.³⁰⁵

Under the Restraint and Seclusion Standard, the initiation of physical restraint, application of seclusion or use of mechanical restraints are only to be on the order of a medical practitioner or nurse practitioner where available, or if not, the most senior clinician on duty.³⁰⁶ In emergency situations where it is necessary to contain risk, the most senior clinical person on duty can make an order for immediate seclusion with an expectation that a medical practitioner or nurse practitioner will review the person as soon as possible to either write an order or discontinue seclusion.³⁰⁷

The Restraint and Seclusion Standard states:

The use of mechanical restraint in inpatient psychiatric settings is considered an extraordinary event. Consideration was given to prohibiting its use, but it is recognised that there will be extremely rare occasions where mechanical restraint will be used to protect the safety of the person and others.³⁰⁸

Each authorisation for mechanical restraint is for a period of 30 minutes, up to a maximum of six authorisations to a total of three hours.³⁰⁹

During patient transport, a paramedic or medical practitioner can approve the use of mechanical restraints when required to protect the safety of the person, health workers and the public. This approval lasts for the duration of the transport. At the hospital, the hospital procedure of medical practitioner approval is required from the time of arrival, even if transfer of care from ambulance to Emergency Department is delayed.³¹⁰

General health

The Minimising Restrictive Practices in Health Care Policy Directive (SA Policy Directive) regulates the use of restrictive practices in health care settings other than mental health settings.³¹¹ It applies to all SA Health employees or persons providing health services or residential care services on behalf of SA Health. While the SA Policy Directive does not apply specifically to people with disability, its application to residential care services (where provided by or on behalf of SA Health) likely extends its operation to some places where people with disability reside.

The SA Policy Directive defines restrictive practices as ‘all the types of restraint, care and control, reasonable force, and seclusion’.³¹² It describes restrictive practices as ‘potentially harmful non-therapeutic interventions’ and states they should not be used as an alternative to proper staffing, equipment or facilities, nor as a punishment or for the convenience of others.³¹³ The SA Policy Directive recognises that use of restrictive practices may have physical and psychological risks for patients and staff.³¹⁴ It encourages staff to focus on ‘prevention strategies and positive changes to the provision of assessment, treatment, care and support’, including retreat, withdrawal and calling for assistance from other staff before applying a restrictive practice.³¹⁵

A plan to use restrictive practices should be initiated and documented by at least two health practitioners, ambulance officers or paramedics.³¹⁶ Where practicable, one of the practitioners should be the treating medical practitioner, although in emergency circumstances two nurses can initiate the use of a restrictive practice.³¹⁷ In these circumstances, an interim plan is made, requiring review and confirmation by a medical officer within one hour.³¹⁸

The use of any restrictive practices must be documented, including the results of clinical assessment, assessment of decision-making capacity, clinical rationale and alternative strategies attempted.³¹⁹ All uses of restraint and seclusion must be reported into the ‘patient incident’ system.³²⁰

Any use of restrictive practices requires consent to be provided by the consumer or, if they are unable to do so, a third party who has authority to do so.³²¹ However, there may be emergency situations where, because of extreme resistive, combative or aggressive behaviour, it is not possible to assess decision-making capacity, obtain consent or safely physically assess the patient without the interim or temporary use of restraint. In these cases, the SA Policy Directive allows the use of restraint without the person's consent, for the purposes of ensuring the safety of all people during the assessment and initial treatment.³²²

The SA Policy Directive provides that restrictive practices should not be used as 'a punishment or for the convenience of others, or as a substitute for adequate surveillance, workers, resources or facilities to provide safe care'.³²³

The SA Policy Directive recognises that the use of restrictive practices without justification is potentially an assault or unlawful imprisonment under criminal and civil law.³²⁴

Tasmania

Mental health

The *Mental Health Act 2013* (Tas) regulates the use of seclusion and chemical, mechanical and physical restraint on involuntary patients other than forensic patients. The Act defines 'seclusion' as 'the deliberate confinement of an involuntary patient or forensic patient, alone, in a room or area that the patient cannot freely exit'. It defines chemical restraint as 'medication given primarily to control a person's behaviour, not to treat a mental illness or physical condition'.³²⁵ Mechanical restraint is 'a device that controls a person's movement' and physical restraint is 'bodily force that controls a person's freedom of movement'.³²⁶

The Chief Civil Psychiatrist's Mechanical and Physical Restraint: Chief Civil Psychiatrist Standing Order 10A (Standing Order 10A) directs controlling authorities, medical practitioners, nurses and other approved hospital and approved assessment centre staff members in the mechanical and physical restraint of involuntary patients under the *Mental Health Act 2013* (Tas), and related matters.³²⁷

Under the *Mental Health Act 2013* (Tas), an involuntary patient who is not a forensic patient may only be placed in seclusion if the seclusion is:³²⁸

- authorised by the Chief Civil Psychiatrist (for a child) or the Chief Civil Psychiatrist, a medical practitioner or approved nurse (for an adult) who is satisfied that it is a reasonable intervention in the circumstances
- undertaken for no longer than the authorised period of time
- managed in accordance with any standing orders issued by the Chief Civil Psychiatrist or clinical guidelines.

Seclusion may only be used to facilitate the patient's treatment, ensure their health or safety or the safety of other persons, or to provide for the management, good order or security of the hospital.³²⁹ Among other conditions, an involuntary patient subject to seclusion must be clinically observed at regular intervals during the seclusion and examined by an approved medical practitioner at four- and 12-hour intervals to determine if the seclusion should be terminated.³³⁰ Seclusion must not extend beyond seven hours unless the patient has been examined by a medical practitioner and the extension of seclusion is authorised by the Chief Civil Psychiatrist.³³¹

The *Mental Health Act 2013* (Tas) provides a separate but similar regime for authorising and using seclusion and restraint on forensic patients.³³² This regime also allows the use of force, only where due to the patient's physical violence, resistance or disturbance, it is necessary to place the patient in seclusion or under restraint.³³³ The use of force must be done only by approved persons and use 'no more excessive, unusual or prolonged than is reasonably justifiable in the circumstances'.³³⁴

Different types of restraint require different authorisation pathways. Under Standing Order 10A, an involuntary patient may only be physically restrained if the restraint is authorised by:³³⁵

- the Chief Civil Psychiatrist or a delegate of the Chief Civil Psychiatrist, if the patient is a child
- the Chief Civil Psychiatrist, a delegate of the Chief Civil Psychiatrist, a medical practitioner or an approved nurse, if the patient is an adult.

An involuntary patient may only be mechanically restrained if the restraint is authorised by the Chief Civil Psychiatrist or a delegate of the Chief Civil Psychiatrist in advance.³³⁶

An involuntary patient is to be physically or mechanically restrained only for the period authorised. In the case of mechanical restraint to transport a patient from one approved facility to another, the period authorised may not exceed seven hours. In all other cases, the period authorised may not exceed three hours.³³⁷

Authorisation is to be obtained at the time the decision to restrain a patient is made, not in advance.³³⁸ Seclusion and the use of chemical, mechanical and physical restraint are subject to review and intervention by the Chief Civil Psychiatrist.³³⁹

The *Mental Health Act 2013* (Tas) imposes a fine not exceeding 100 penalty units or imprisonment for a term not exceeding one year for the 'unlawful treatment' of a patient.³⁴⁰ 'Unlawful treatment' is defined as treatment 'given without informed consent or, in the absence of informed consent, authorisation under this Act or any other law'.³⁴¹

General health

While Tasmania has a list of compulsory guidelines and policies for general health settings, there are none for the use of restrictive practices in health settings not related to care and treatment under the *Mental Health Act 2013* (Tas).

Victoria

Mental health

The Mental Health and Wellbeing Bill 2022 (Vic) passed Victorian Parliament on 30 August 2022 and was given royal assent on 6 September 2022.³⁴² It is expected to come into force by 1 September 2023, when it will repeal the *Mental Health Act 2014* (Vic).³⁴³

The *Mental Health and Wellbeing Act 2022* (Vic) was informed by the findings of the Royal Commission into Victoria's Mental Health System (Victorian Royal Commission).³⁴⁴ The objectives of the Act include the aim of eliminating of restrictive practices within 10 years, consistent with a recommendation made by the Victorian Royal Commission.³⁴⁵ However, as the Explanatory Memorandum for the Bill states, targets for the reduction of restrictive practices will be 'set outside of the legislation to provide flexibility to progress at a rate that allows for the safety of services, consumers and staff to be maintained'.³⁴⁶

The *Mental Health and Wellbeing Act 2022* (Vic) defines a 'restrictive intervention' as 'seclusion, bodily restraint or chemical restraint'.³⁴⁷ In doing so, the Act regulates the use of chemical restraint in mental health services in Victoria for the first time.³⁴⁸ It defines chemical restraint as 'the giving of a drug to a person for the primary purpose of controlling a person's behaviour by restricting their freedom of movement', which does not include giving a drug to a person for the purpose of treatment or medical treatment.³⁴⁹

The *Mental Health and Wellbeing Act 2022* (Vic) is unique in recognising that the use of restrictive interventions (and compulsory assessment or treatment) 'significantly limits a person's human rights and may cause possible harm'.³⁵⁰ The Act also provides that using restrictive interventions 'offers no inherent therapeutic benefit to the person'.³⁵¹ It prohibits their use 'unless the serious harm or deterioration to be prevented is likely to be more significant than the harm to the person that may result from their use'.³⁵²

A restrictive intervention must only be used if necessary to prevent imminent and serious harm to the person or in cases of 'bodily restraint', to administer medical treatment to the person.³⁵³ In such cases, all reasonable and less restrictive options must first be tried or considered and found unsuitable.³⁵⁴

Use of the restrictive intervention must be authorised by an authorised psychiatrist, or if a psychiatrist is not reasonably available, a registered medical practitioner or a nurse in charge.³⁵⁵ The authorising psychiatrist must ensure use of the restrictive intervention is reviewed as soon as practicable after it ends.³⁵⁶ They must provide written reports to the chief psychiatrist on the use of restrictive interventions.³⁵⁷

General health

In Victoria, no legislation or policy currently addresses the use of restrictive practices in general health settings. The relevant laws are directed only to the use of 'restrictive interventions' under the *Mental Health Act 2014* (Vic).³⁵⁸

Western Australia

Mental health

The *Mental Health Act 2014* (WA) authorises the use of seclusion and bodily restraint (being physical or mechanical restraint)³⁵⁹ of a person who is ‘being provided with treatment or care at an authorised hospital’.³⁶⁰ This applies to all adults and children receiving mental health services.³⁶¹

A patient may be kept in seclusion on the basis of either a seclusion order or the oral authorisation of a medical practitioner, or in the case of an emergency, a mental health practitioner or person in charge of a ward.³⁶² Neither a seclusion order nor an oral authorisation can be made unless the relevant person is satisfied the patient needs to be secluded to prevent them from physically injuring themselves or another person, or persistently causing serious damage to property.³⁶³ There must also be no less restrictive way of preventing the injury or damage.³⁶⁴

The seclusion may only continue for two hours, subject to a further two hours’ extension.³⁶⁵ The person must be observed by a mental health practitioner or nurse every 15 minutes, and by a medical practitioner at least every two hours.³⁶⁶ They must also be provided with certain basic necessities during this time.³⁶⁷ The person must also be examined by a medical practitioner within six hours of their release.³⁶⁸

The *Mental Health Act 2014* (WA) also provides for the use of physical or mechanical restraint (collectively ‘bodily restraint’) in accordance with oral authorisation or a seclusion order.³⁶⁹ Physical restraint is restraint of a person by application of bodily force to restrict the person’s movement, while mechanical restraint is the restraint of a person by application of a device – such as a harness or strap – to restrict their movement.³⁷⁰ Where bodily restraint is used, it must involve the minimum degree of force, and least possible restriction of the person’s movement.³⁷¹ The Act requires that a person be ‘treated with dignity and respect’ while they are restrained.³⁷²

General health

In Western Australia, no publicly available policy or procedure documents apply to the use of restraint in health settings except treatment of patients requiring mental health care or under the direction of a public health order.³⁷³

Education settings

There is no Commonwealth law, policy or guideline about when restrictive practices may be used in education settings. The use of restrictive practices in preschools, primary and secondary education is regulated at state and territory level.

In all jurisdictions other than Victoria and the Australian Capital Territory, policy and procedures – rather than legislation – specify the circumstances in which restrictive practices may be used in government schools. The use of restrictive practices in non-government schools is governed by policies and procedures, either at the individual school level or system level.³⁷⁴ Some of these are not publicly available.

Australian Capital Territory

The *Senior Practitioner Act 2018* (ACT) provides the framework for the authorisation of restrictive practices in both government and non-government schools. The Act applies to education settings the same way as it does to disability service settings (discussed earlier in this section).³⁷⁵

In education settings, the Act also provides that the person with disability, or any other person whose interests are affected, has the right to apply for independent review of a decision to authorise the use of restrictive practices.³⁷⁶ This review is by the ACT Civil and Administrative Tribunal.

New South Wales

The New South Wales Department of Education's Restrictive Practices Framework provides that in government schools and preschools, restrictive practices must only be used:³⁷⁷

- in the way they have been recommended or prescribed by an external medical practitioner, allied health professional or external behaviour support practitioner
- as a last resort, after less restrictive approaches and strategies have been tried.

The Restrictive Practices Framework identifies five categories of restrictive practice, being chemical restraint, mechanical restraint, physical restraint, environmental restraint and seclusion.³⁷⁸ It broadly defines 'restrictive practice' as 'any action that has the effect of restricting the rights or freedom of movement of a person, with the primary purpose of protecting the person or others from harm'.³⁷⁹

Staff must apply six principles in the Restrictive Practices Framework when deciding whether to use restrictive practices.³⁸⁰ These principles are:³⁸¹

- a **student-centred** approach, which focuses on evidence and consultation with the student. Consideration should be given to potential child protection/trauma issues, as well as culture, religion, beliefs, linguistic circumstances, disability and gender
- ensuring restraints used are the **least restrictive** possible to meet the individual needs of the student
- using restraints for the **shortest time** needed to ensure the safety of the student and others, with the aim of reducing or eliminating their use over time, wherever possible

- helping to **reduce and eliminate** restrictive practices, particularly considering if there are other options available
- **monitoring** to ensure use of a restrictive practice remains consistent with actions originally approved, planned and consented to, that risk is being safely managed, and the practice is used for the shortest time possible
- regular **review** to make sure the restrictive practice is still needed and to reduce risk associated with it.

At the time of writing, the Restrictive Practices Reduction and Elimination policy governed the use of restrictive practices in government schools and preschools. Subsequently, the New South Wales Department of Education announced the policy is not in force and is under review.³⁸² The policy identified six practices prohibited in New South Wales public schools and government preschools:³⁸³

- planned seclusion or seclusion that is used outside of an emergency or crisis response
- denial of key needs such as water and food
- using restrictive practices as a form of discipline or threat, for reasons of convenience or as punishment
- life-threatening physical restraints
- misuse of medication
- use of a restrictive practice that has not been planned, consulted and consented to, except in an emergency or crisis where a duty of care obligation exists.

The Restrictive Practices Reduction and Elimination policy distinguished between planned and unplanned use of restrictive practices. A planned restrictive practice was permitted where consent had been given by parents or carers, the practice was only used as recommended by an external medical or behaviour support practitioner, and the ongoing use of the practice had been planned in consultation with the student and their parents.³⁸⁴ Where an unplanned restrictive practice was used in response to an emergency, or where a planned restrictive practice was used other than in compliance with the policy, the principal had to report it to the Incident Report and Support Hotline, notify the parents or carers of the child and undertake an incident review.³⁸⁵

The policy also considered general consequences that may follow the unauthorised use of a restrictive practice, including 'potential criminal offences, a breach of duty of care obligations, and/or disability discrimination'.³⁸⁶

Northern Territory

The Northern Territory Protective Practices Guideline outlines circumstances in which teachers in government or non-government schools may use physical restraint on a child.³⁸⁷ The Protective Practices Guideline provides that teachers may use physical restraint if all non-physical interventions have been exhausted or are impossible in the circumstances and a child or young person is 'attacking another child or young person or adult, or posing an immediate danger to him/herself or others'.³⁸⁸

The Protective Practices Guideline also provides that physical restraint must only be used as a last resort, it must be reasonable and proportionate to the circumstances, and must be the minimum force needed to achieve the desired result.³⁸⁹

The Protective Practices Guideline specifies that appropriate physical force may be permitted to ensure that the employer's duty of care to protect children and young people and staff from foreseeable risks of injury or harm is met.³⁹⁰ The Protective Practices Guideline recognises that use of physical restraint may be a criminal offence, and that common law defences such as self-defence and defence of others can justify the use of physical restraint.³⁹¹

Queensland

Queensland's Restrictive Practices Procedure regulates restrictive practices procedures in government schools.³⁹² The Restrictive Practices Procedure notes state school staff have a non-delegable duty of care to take reasonable action to prevent the risk of foreseeable harm to students, themselves and other persons. Generally, restrictive practices permitted under this procedure may only be used where the restrictive practice is reasonable in all the circumstances and there is no less restrictive measure available to respond to the behaviour in the circumstances.³⁹³

State school staff may only use seclusion or unplanned physical restraint where:³⁹⁴

- the student is behaving in a way that poses an immediate foreseeable risk of harm to themselves or others
- the seclusion or physical restraint is reasonable in all the circumstances as a response to the student's behaviour
- there is no less restrictive measure available to respond to the student's behaviour in the circumstances.

For the use of a seclusion or physical restraint to be 'reasonable', the seclusion or physical restraint must be:³⁹⁵

- proportionate to the risk of harm
- discontinued once the risk of harm has dissipated
- respectful of the student's dignity.

Mechanical restraint can be used as a planned restrictive practice for reducing or controlling a student's serious and repetitive self-injurious behaviour.³⁹⁶

Clinical holding, a type of physical restraint necessary 'in order to provide essential healthcare or personal care',³⁹⁷ may also be used in certain circumstances.³⁹⁸

The Restrictive Practices Procedure also distinguishes between planned and unplanned uses of restrictive practices. Any use of planned restraint must be supported by an individual

behaviour support plan. This must be informed by a documented rationale, supported by a strategy for reducing the use of the planned restraint and developed in consultation with the student's parents.³⁹⁹

If a restrictive practice is used on a student, a member of the leadership team at the school should conduct a Focused Review of the incident as soon as possible.⁴⁰⁰ Focused Reviews aim to consider everyone's safety and wellbeing, determine whether the use of the restrictive practice was appropriate in the circumstances and develop strategies to respond better to the student's behaviour in the future.⁴⁰¹ The school leadership team must keep a record of the Focused Review and actions taken as a result.⁴⁰²

Where seclusion or unplanned physical restraint is used, the school must report the use to the parents or guardians of the student who was subject to the practice and conduct a Focused Review.⁴⁰³ Additionally, where a principal is of the reasonable belief a state school staff member used a restrictive practice that was inappropriate in the circumstances or not compliant with Queensland's Restrictive Practices Procedure, they must provide details of the incident to their supervisor or delegate as soon as practicable.⁴⁰⁴

South Australia

In South Australia, the Behaviour Support Policy provides that:

- exclusionary responses, such as suspension or part-time attendance, are used as a last resort⁴⁰⁵
- staff must take special measures to support the inclusion of children and young people who are at higher risk of exclusionary responses to their behaviours, including children with disabilities.⁴⁰⁶

The Protective practices for staff in their interactions with children and young people: Guidelines for staff working or volunteering in education or care settings (SA Protective Practices Guidelines) govern the use of physical restraint and restrictive practices for children in government and non-government schools. The SA Protective Practices Guidelines state that such practices may only be used against a child or young person in situations where the safety of others is threatened or to prevent injury.⁴⁰⁷

The SA Protective Practices Guidelines do not define physical restraint. However, the restraint must:⁴⁰⁸

- be reasonable in the particular circumstances and must be in proportion to the circumstances of the incident
- always be the minimum force needed to achieve the desired result
- take into account the age, stature, disability, understanding and gender of the child or young person.

Parents should be informed at enrolment of the site's policy on physical restraint and restrictive practices for children and young people.⁴⁰⁹

The SA Protective Practices Guidelines provide that where physical restraint is used, the use should be promptly documented and records kept.⁴¹⁰ Any sector-specific guidelines concerning other documentation must also be followed.⁴¹¹

Tasmania

In Tasmania, the Restrictive Practices Policy and the Restrictive Practices Procedure set out 'expectations of [government] school staff and principals in managing at-risk behaviour, with the intent that restrictive practices will only be used as a last resort and as part of an individualised approved planned strategy'.⁴¹²

The Restrictive Practices Policy defines restrictive practices as the 'use of interventions or strategies that have the effect of restricting the rights or freedom of movement of a student'.⁴¹³ It provides that:⁴¹⁴

- restrictive practices must only be used as a last resort and to ensure the safety of the student or any other person
- students' rights must be upheld
- students must be treated with dignity and respect.

The Restrictive Practices Policy specifies that restrictive practices include seclusion, physical restraint, containment, mechanical restraint, chemical restraint and clinical holding.⁴¹⁵ The Restrictive Practices Procedure states that if a school is proposing the planned physical restraint, seclusion, containment, mechanical restraint or clinical holding in respect of a particular student, the school must develop a De-escalation Response Plan. The De-escalation Response Plan must be read in conjunction with any behaviour support strategies, communication support strategies or risk mitigation strategies included in a student's Risk Management Plan.⁴¹⁶

Physical restraint or seclusion may only be used where the student's behaviour poses a serious and imminent risk of harm to themselves or others, the seclusion or physical restraint is reasonable in the circumstances and there is no less restrictive measure available. It must be proportionate to the risk of harm and discontinued once the risk of harm has dissipated.⁴¹⁷

Containment must only be used as a short-term planned strategy where the student presents a risk of harm to themselves or others.⁴¹⁸ Mechanical restraint can be used as a planned restrictive practice to reduce or control serious and repetitive self-injurious behaviour, and where:⁴¹⁹

- there is a foreseeable risk of harm
- the device has been prescribed by a health professional
- other less restrictive approaches have been tried or considered and found to be ineffective
- parents have approved the use of mechanical restraint
- staff have been trained in how to use the prescribed device.

Clinical holding can only be used if it is used in accordance with a plan approved by the student's parents, there are no other alternatives, and it is appropriate and reasonable in the circumstances.⁴²⁰

Victoria

Victoria is the only jurisdiction which explicitly requires non-government schools to have policies and procedures regarding the use of restrictive practices. In Victoria, all schools – whether government, Catholic or independent – operate under the same legislative and regulatory requirements.⁴²¹ However, some provisions of the legislation and regulations are directed only to government schools.

Regulation 25 of the *Education and Training Reform Regulations 2017* (Vic) regulates the practice of physical restraint and seclusion in schools. No other use of restrictive practices is allowed under the Regulations. The Victorian Government has also published advice that explains administering *pro re nata* (PRN), or 'as needed', medication to a student to control their behaviour is not permitted in government schools, although this is distinguished from medication 'given at a set time or series of times according to a schedule'.⁴²² The advice otherwise explains that schools cannot require parents or carers to obtain medication for a child as a condition of enrolment.⁴²³ It says that medication used to control students' behaviour can have serious side effects that can negatively affect a student's educational experience.⁴²⁴

Regulation 25 states that 'A member of staff of a Government school may take any reasonable action that is immediately required to restrain a student of the school from acts or behaviour that are dangerous to the member of staff, the student, or any other person.'⁴²⁵ Regulation 26C contains an equivalent provision applying to government school boarding premises.

The Victorian Department of Education Restraint and Seclusion Policy 2022 sets out further principles to guide the use of physical restraint and seclusion in an education setting. The Policy provides that the planned use of restraint or seclusion may never be used as part of a behaviour management response.⁴²⁶

The Principles for Reduction and Elimination of Restraint and Seclusion in Victorian Government Schools are designed to reduce and eventually eliminate the use of restraint and seclusion in Victorian government schools. The Principles state that every effort should be made to prevent the need for the use of physical restraint or seclusion. They state that physical restraint and seclusion are not permitted within Victorian government schools, except:⁴²⁷

- in situations where the student's behaviour poses an imminent threat of physical harm or danger to self or others
- where such action would be considered reasonable in all the circumstances
- where there is no less restrictive means of responding in the circumstances.

The Principles state any behavioural intervention must be consistent with the *Charter of Human Rights and Responsibilities Act 2006* (Vic) and the student's rights to be treated with dignity

and to be free from abuse.⁴²⁸ All instances of restraint should be the least restrictive option reasonably available in the circumstances, be justified and proportionate, and cease once the immediate threat of harm has passed.⁴²⁹

Western Australia

In Western Australia, there is no policy or legislation which expressly addresses the use of restrictive practices in education settings. However, the *School Education Regulations 2000* (WA) state that school staff may, in certain circumstances, use physical contact with students. Staff can take reasonable action, including physical contact with a student or a student's property, to prevent or restrain a person from placing at risk the safety of any person or damaging any property.⁴³⁰ The Regulations make no reference to disability.

The Physical Contact with Students Policy also refers to planned physical intervention, which is described as the 'use of physical intervention as the last resort in managing student behaviour'.⁴³¹ Planned physical intervention must be used as a last resort in managing student behaviour, only when in the child's best interests and when it is reasonable, necessary and proportionate in the circumstances.⁴³² This type of intervention requires prior consultation with parents or guardians and must be documented in the student's behaviour support plan.⁴³³ Reports of incidents where physical contact is used should be made to the principal at the earliest opportunity both verbally and in writing.⁴³⁴

The Physical Contact with Students Policy also provides school staff may engage in physical contact where non-physical interventions are impractical in the circumstances and have all been exhausted and the student is attacking an adult or student, posing an immediate danger to others or themselves, or damaging property.⁴³⁵ In these situations, staff may only use physical contact as a last resort and not in response to verbal threats, or to ensure compliance.⁴³⁶

The Physical Contact with Students Policy lists unacceptable practices relating to interaction with students with 'identified needs', including use of physical contact to contain confrontational student behaviour, particularly of students with identified behaviour or conduct disorders, unless there are safety concerns for the student, other students or staff.⁴³⁷

Justice settings

All states and territories have enacted primary or subordinate legislation governing the use of force in prisons and juvenile detention. Use of force includes some forms of what would be considered restrictive practices – for example, the use of restraints including handcuffs. Some jurisdictions have specific provisions on the use of restraints and administration of medication.⁴³⁸

In prisons and juvenile detention, force and restraint are generally used to manage prisoners (adults), detainees (children and young people) or the detention environment. For example, in New South Wales, order and discipline are to 'be maintained with firmness, but with no more restriction or force than is required for safe custody and well-ordered community life within the [correctional] centre'.⁴³⁹ Prison officers in the Northern Territory may use force that is reasonably

necessary to maintain the security and good order of a prison and prisoners.⁴⁴⁰ The Queensland *Corrective Services Act* (2006) provides that corrective services officers may use force that is reasonably necessary to compel compliance with an order given to a prisoner.⁴⁴¹

All prisons and juvenile detention centres also use environmental restraints in the form of cells, blocks and general building design, because they necessarily must control the movement of prisoners and detainees within and outside the prison or detention centre.

Generally, all legislation authorising the use of force is directed to the restraint of a prisoner by a prison or youth detention officer. It does not specifically contemplate the use of force or restraint on people with disability.

Australian Capital Territory

In the Australian Capital Territory, the *Corrections Management Act 2007* (ACT) regulates the use of restraints against prisoners,⁴⁴² and the circumstances in which the use of force is justified.⁴⁴³ The Act provides that the use of a restraint must be proportionate to the circumstances, and must be used in accordance with a relevant policy or operating procedure.⁴⁴⁴ Restraints include body contact, handcuffs, restraint jackets and other restraining devices.⁴⁴⁵ As far as practicable, the use of force (including restraints) should be a last resort.⁴⁴⁶

The *Corrections Management Act 2007* (ACT) also provides that a health practitioner may administer a drug as a restraint if the practitioner believes, on reasonable grounds, that it is necessary and reasonable to treat a prisoner, prevent a prisoner from causing harm to themselves or to prevent their escape.⁴⁴⁷

The *Corrections Management Act 2007* (ACT) provides that separate confinement can be imposed on a detainee as a penalty for a disciplinary breach.⁴⁴⁸ However, the Standards for Adult Correctional Services provide that:⁴⁴⁹

- separate confinement and segregation is not used on detainees with mental health conditions without prior consultation with a mental health professional, except in exceptional circumstances
- detainees in separate confinement are regularly visited by health professionals who must advise if termination or alteration of segregation is necessary on grounds of physical or mental health or disability.

The Standards for Adult Correctional Services include a standard requiring that ‘the specific needs of detainees with a disability are met’, including the provision of reasonable adjustments.⁴⁵⁰ However there is no specific guidance regarding the use of restrictive practices on detainees with disability.

The *Children and Young People Act 2008* (ACT) authorises a youth detention officer to use physical restraints, such as handcuffs or restraint jackets, against a child in detention.⁴⁵¹

As far as practicable, the use of force involving a restraint must be proportionate to the circumstances.⁴⁵² Each month, youth detention officers must provide a report summarising the incidents of restraints or force (if any) during the month.⁴⁵³

A detainee in youth detention may apply to an external reviewer for review of a direction to segregate them from other young detainees.⁴⁵⁴ An external reviewer is a magistrate appointed by the Minister to the role.⁴⁵⁵

New South Wales

There are no disability-specific provisions in legislation or regulations on the use of restrictive practices in justice settings. However, the *Crimes (Administration of Sentences) Regulation 2014* (NSW) contains general provisions that govern ‘use of force in dealing with inmates’ and ‘use of equipment for restraining inmates’.⁴⁵⁶ Some of the allowable instances of use of force are similar to the circumstances in which restrictive practices may be used in other settings, for example, to prevent an inmate injuring themselves or harming others.⁴⁵⁷

The Regulation provides that a prison officer, with the agreement of the general manager, may use handcuffs, security belts, batons, chemical aids and firearms for the purpose of restraining inmates.⁴⁵⁸ Any prison officer who uses force on a prisoner must provide a written report to the general manager describing the nature of the force and the circumstances requiring its use.⁴⁵⁹

The use of force against children and young people in detention centres is governed by the *Children (Detention Centres) Regulation 2015* (NSW). The Regulation provides that a juvenile justice officer must not use force against a child in juvenile detention, except for specified purposes.⁴⁶⁰ The listed purposes include to prevent a detainee from hurting themselves or others.⁴⁶¹ The juvenile justice officer must not use any more force than is reasonably necessary, and the infliction of injury on the detainee is to be avoided if possible.⁴⁶² As soon as practicable after force has been used, a report must be provided to the manager of the detention centre.⁴⁶³

There are limits on the segregation of youth detainees, regardless of disability status. Segregation may be used to protect the safety of the detainee or others, however the duration must be as short as practicable, may not be used as punishment and must not exceed three hours except with the approval of the Secretary.⁴⁶⁴

Northern Territory

The *Correctional Services Act 2014* (NT) authorises prison officers to use the force that is reasonably necessary to maintain the security and good order of a prison and adult prisoners.⁴⁶⁵ A prison officer may also restrain any prisoners causing a disturbance at the facility.⁴⁶⁶ The Act does not identify the types of restraints permitted. However, it does provide for the administration of medication to a prisoner where this is necessary to prevent or reduce the risk of a prisoner causing harm to themselves or others, and is the least restrictive intervention available in the circumstance, based on advice from a medical practitioner.⁴⁶⁷

The *Youth Justice Act 2005* (NT) provides that force may only be used against a child in detention where:⁴⁶⁸

- all other reasonably practicable measures to resolve the situation have been attempted and those measures have failed to resolve the situation
- the person using the force gives a clear warning of the intended use of force, and
 - allows a reasonable amount of time for the child to observe the warning
 - uses no more force that is necessary and reasonable in the circumstances
 - holds a current qualification in physical intervention techniques on children.

For the purpose of considering what force is necessary or reasonable, the Act directs the person authorised to use it to consider the age, gender, physical and mental health or background of the child.⁴⁶⁹

The *Youth Justice Act 2005* (NT) provides that handcuffs, ankle cuffs and waist restraining belts are the only forms of ‘approved restraints’.⁴⁷⁰ The superintendent of a detention centre may authorise ‘appropriate use’ of an approved restraint where they believe on reasonable grounds that it is necessary to:⁴⁷¹

- prevent an imminent risk of the detainee inflicting self-harm, harming another person or seriously damaging property
- prevent the detainee from engaging in conduct that would endanger the safety of any person within the detention centre (including the detainee) or seriously threaten the security of the detention centre.

They may also authorise appropriate use of the restraint if they believe on reasonable grounds that the detainee is likely to attempt escaping the detention centre, or attempt escaping while being escorted outside the detention centre.⁴⁷²

‘Appropriate use’ of the approved restraint means using it in the least restrictive or invasive way possible, for the minimum time reasonable in the circumstances and in accordance with any regulations governing use of approved restraints.⁴⁷³

The superintendent may also authorise the ‘separation’ of a detainee if the detainee requests to be separated and the superintendent is satisfied there is good reason for the separation, if the detainee is believed to be suffering from an infectious disease, or it is reasonably necessary for the detainee’s protection or protection of another person or property.⁴⁷⁴ In the last case, authorisation may only be given if all reasonable behavioural or therapeutic measures to resolve the situation have been attempted and failed, and no other course of action is reasonably practicable.⁴⁷⁵ In those cases, a detainee may not be separated for more than 12 hours without the approval of the CEO, and otherwise they cannot be separated for more than 72 consecutive hours.⁴⁷⁶

Queensland

In Queensland, the *Corrective Services Act 2006* (Qld) provides that a prison officer may use force (including a restraining device) that is reasonably necessary in certain circumstances.⁴⁷⁷ These include restraining a prisoner who is harming or attempting to harm themselves.⁴⁷⁸ The Act also prescribes certain weapons or restraints which can be used against a prisoner, including use of a physical restraining device.⁴⁷⁹ An order for a prisoner to undergo separate confinement must take into account any special needs of the prisoner, and not be for more than seven days.⁴⁸⁰

Queensland has a Forensic Disability Service, which accommodates up to 10 people who have a cognitive disability and who are subject to a forensic order. The *Forensic Disability Act 2011* (Qld) provides:

- a senior practitioner who is a doctor or registered nurse may administer behaviour control medication if it has been prescribed by a psychiatrist⁴⁸¹
- the director may authorise the use of restraint if it is the least restrictive way to protect the client's health and safety or to protect others, and must have regard to the client's individual development plan⁴⁸²
- a senior practitioner (or an authorised practitioner in urgent circumstances) may authorise seclusion if necessary to protect the client or others from imminent physical harm and there is no less restrictive way,⁴⁸³ and must have regard to the client's individual development plan.⁴⁸⁴

The *Youth Justice Regulation 2016* (Qld) provides that an authorised staff member may use approved restraints to restrain a child they reasonably believe is likely to attempt to escape, seriously harm themselves or others, or seriously disrupt order and security.⁴⁸⁵ If restraints are used, all reasonable steps should be taken to respect the child's dignity, and restraints should not be used for longer than is reasonably necessary.⁴⁸⁶ A record must be made of any restraints used.⁴⁸⁷

A detention centre employee may separate a child in a locked room for the child's protection or to protect another person or property, or to restore order.⁴⁸⁸

South Australia

In South Australia, the *Correctional Services Act 1982* (SA) authorises the use of force and restraint against a prisoner. It provides that an officer or employee of the Department or a police officer employed in a correctional institution may, for the purposes of exercising powers or discharging their duties, use such force as is reasonably necessary in the circumstances.⁴⁸⁹ Restraints can also be used on prisoners in certain circumstances, including during the transfer of prisoners between prisons.⁴⁹⁰ A prisoner may only be kept 'separate and apart' from all other prisoners in certain circumstances, including if this is in the interests of the prisoner's welfare or safety, or to protect other prisoners, for a period of up to 30 days (with the potential for extension in some circumstances).⁴⁹¹

The *Youth Justice Administration Act 2016* (SA) regulates the use of force against children in detention or ‘youth training centres’. An employee of a training centre may only use such force against a detainee as is reasonably necessary in a particular case.⁴⁹² The Act specifies the circumstances in which use of force is justified, such as to maintain order in the training centre.⁴⁹³ If force is used against a detainee, a written report must be provided to the manager of the centre.⁴⁹⁴ The manager of the centre must ensure the child is examined as soon as practicable by a health professional.⁴⁹⁵

Tasmania

The *Corrections Act 1997* (Tas) regulates the use of force against prisoners by prison officers. The use of force involving a restraint or weapon must, as far as practicable, be proportionate to the circumstances.⁴⁹⁶ Specifically, the circumstances must be sufficiently serious to justify the use, and the kind of restraint or weapon and its use must be appropriate in the circumstances.⁴⁹⁷ A prison officer may use force for the reasons listed in the Act, including to prevent a prisoner from inflicting self-harm.⁴⁹⁸ The Director of Corrective Services must keep a record of any incident involving use of force that causes injury or death, and provide the record to the Coordinator of the Official Visitors Scheme for the purpose of informing the official visitors as soon as practicable after the incident.⁴⁹⁹

The use of force against children in detention is governed by the *Youth Justice Act 1997* (Tas). Physical force is generally prohibited, unless it is reasonable and either:⁵⁰⁰

- necessary to prevent the detainee from harming himself or herself or anyone else
- necessary to prevent the detainee from damaging property
- necessary for the security of the centre
- otherwise authorised.

A detention centre manager may authorise the isolation of a detainee if either:⁵⁰¹

- the detainee’s behaviour presents an immediate threat to safety or property and all other reasonable steps have been taken but have been unsuccessful
- it is in the interests of the security of the centre.

A detainee placed in isolation must be supervised and observed every 15 minutes.⁵⁰²

Victoria

In Victoria, the Governor of a prison is conferred powers and functions under the *Corrections Regulations 2019* (Vic).⁵⁰³ For example, the Governor may direct a prison officer to use an instrument of restraint against a prisoner if the Governor believes on reasonable grounds that the use of the instrument of restraint is necessary for the safety of the prisoner or any other

person, or for the security or good order of the prison.⁵⁰⁴ An instrument of restraint can include:⁵⁰⁵

- handcuffs
- arm restraints
- leg restraints
- belts which restrain part of the body
- spitter protective hoods
- one or more chains and a fixture.

The Governor is obliged to notify the Secretary of the Victorian Department of Justice and Community Safety if the instrument of restraint is applied to a prisoner for a continuous period of more than 18 hours, or for a cumulative period of 36 hours in any 96-hour period.⁵⁰⁶ When applying an instrument of restraint to a prisoner who is under the age of 18, the prison officer must, if reasonably practicable, consider – among other factors – the ‘vulnerability’ of the prisoner.⁵⁰⁷ The *Corrections Regulations 2019* (Vic) do not define vulnerability.

In youth detention, the *Children, Youth and Families Act 2005* (Vic) provides that reasonable force may be used against detainees if reasonable and necessary to prevent harm, or for security.⁵⁰⁸ Isolation of detainees may only be authorised by the officer in charge if all other reasonable steps have been taken to prevent harm or damage to property, and the detainee’s behaviour presents an immediate threat to safety or property.⁵⁰⁹

The following actions are prohibited under the Act:⁵¹⁰

- use of isolation as a punishment
- use of physical force unless reasonable and necessary to prevent harm or for security
- use of corporal punishment
- any form of psychological pressure intended to intimidate or humiliate, and the use of any form of physical or emotional abuse
- use of any kind of discriminatory treatment.

Western Australia

In Western Australia, the *Prisons Act 1981* (WA) governs the use of restraints against adult prisoners. The Act authorises a prison superintendent to direct the restraint of a prisoner where it is necessary to prevent a prisoner injuring himself or any other person, to prevent the escape of a prisoner, or, upon considering advice from a medical officer or some other medical practitioner, on medical grounds.⁵¹¹ The Act does not define restraint.

If restraint is used for a continuing period of more than 24 hours, the use and the circumstances must be reported to the Chief Executive Officer.⁵¹² The Chief Executive Officer is employed

by the Department of Communities. The Act designates the Chief Executive Officer the responsibility for the management, control, and security of all prisons and the welfare and safe custody of all prisoners.⁵¹³

The *Prisons Act 1981* (WA) also authorises the use of force against a prisoner where the Chief Executive Officer is of the opinion that a serious breach of the good order or security of a prison is imminent or has occurred and no other reasonable means of control are available.⁵¹⁴ In carrying out the duties, powers and functions provided in the Act, prison staff will be protected from criminal or civil liability unless they have acted maliciously or without reasonable and probable cause.⁵¹⁵

The *Prisons Act 1981* (WA) provides a prisoner may be held in separate confinement for no longer than 30 days, with at least one hour per day for ‘taking air and exercise’.⁵¹⁶

The *Young Offenders Act 1994* (WA) provides that restraint of a detainee may be authorised when necessary to prevent them from injuring themselves or others, on medical grounds or to prevent escape from a facility or detention centre.⁵¹⁷ Restraint involving the use of medication may only be used with the approval of a medical practitioner.⁵¹⁸

5.4. Restrictive practices and people with disability

People with disability, particularly people with cognitive disability, can be subjected to restrictive practices by registered NDIS providers, by healthcare providers, in schools and in prisons or juvenile detention.

In this section we discuss:

- evidence from people with disability and their supporters about their experiences of restrictive practices
- data concerning the use of restrictive practices
- systemic drivers of the use restrictive practices.

Experiences of restrictive practices in different settings

Supported accommodation

At several hearings, we heard that people with disability living in supported accommodation have been subjected to restrictive practices.⁵¹⁹ At Public hearing 6, a witness said her brother’s behaviours escalated in supported accommodation. Staff responded by applying environmental or chemical restrictive practices, rather than addressing the circumstances prompting his behaviours.⁵²⁰

At the same hearing Ms Dariane McLean said disability support staff at her son’s supported accommodation used restrictive practices against her son when he acted in a way they saw as

‘uncooperative’. She described a range of environmental restraints they used, including locking kitchen cupboards, doors and windows.⁵²¹

Ms McLean’s son was also prescribed psychotropic medication without her knowledge or consent.⁵²² Ms McLean recounted:

While my son was at the first group home, there were occasions when my son was overmedicated to the point that he was very unwell ... I also would notice when attending to collect my son for outings that he was often under the heavy influence of medication that did not seem in line with his treatment plans.⁵²³

Ms Sarah Forbes, Advocacy Manager at Victorian Advocacy League for Individuals with Disability (VALiD), provided an example of a client who was ‘demonised’ for his behaviour while living in group homes and was consequently subjected to restrictive practices. She said ‘that behaviour went away when he moved into his own home’.⁵²⁴

Ms Rosemary Atherton shared the experience of her late brother, Mr Glen Hardwick who lived with an intellectual disability.⁵²⁵ Mr Hardwick lived in supported accommodation and was prescribed a range of unspecified psychotropic medication for his behaviours, such as skin picking. Ms Atherton said her brother became like ‘a zombie’, but improved after coming off the medication.⁵²⁶

As noted above, the use of medication to suppress menstruation in response to certain behaviour of a person with disability, such as expressing distress, is considered a chemical restraint.⁵²⁷ At Public hearing 17, ‘The experience of women and girls with disability with a particular focus on family, domestic and sexual violence’, Ms Carolyn Frohmader, Executive Director of Women With Disabilities Australia, told us she understands that menstrual suppression is being widely used in group homes and segregated settings.⁵²⁸ She said she knows of women with disability ‘on long-acting injectable contraceptives like Depo-Provera injections ... with no clinical indication whatsoever’. She said some of these women have been ‘told things like it’s the flu injection’.⁵²⁹

Hospitals

At Public hearing 6, we heard about Oliver McGowan, a young person with disability who experienced partial seizures. Oliver lived in the United Kingdom, but sadly passed away at the age of 18 years. Throughout his life, antipsychotic medications were administered in response to his ‘normal autistic behaviours’, even though he was never diagnosed with a mental illness or psychosis.⁵³⁰ The medications were also administered against the wishes of Oliver and his parents.⁵³¹ Oliver was sensitive to the antipsychotic medication. This meant he suffered increased seizures, hallucinations and high blood pressure.⁵³² We discuss over-prescription and over-use of psychotropic medication as a response to ‘behaviours of concern’ by people with cognitive disability in Section 5.6.

We heard that restrictive practices are sometimes used in health settings because the clinical adaptations that a person with disability needs are not made. For example, Ms Sabrina

Monaghan described an instance where her son was physically restrained and sedated by hospital staff.⁵³³ Ms Monaghan described these events as ‘absolutely heart breaking, both for me as a mother and for [my son]’.⁵³⁴

Ms Rachael Browne provided a written statement ahead of Public Hearing 4. She described the experiences of her son, Finlay, who had a disability, during hospital admissions. Finlay sadly passed away at 16 years of age. Ms Browne said, instead of giving Finlay ‘more time, a caring bedside manner, social stories, quiet surroundings, and an explanation of what was about to happen’, he was subjected to physical restraints such as people holding him, restricting him and pinning him down.⁵³⁵ Ms Browne said these experiences were ‘terrifying, inhumane and degrading’.⁵³⁶

Schools

Witnesses told us that school students with disability may be subjected to seclusion and physical and mechanical restraint in response to their behaviours.⁵³⁷ At Public hearing 7, ‘Barriers experienced by students with disability in accessing and obtaining a safe, quality and inclusive school education and consequent life course impacts’, we received evidence about:

- ‘Leif’, a young person with disability who was physically restrained in response to behaviours triggered by bullying from other students⁵³⁸
- Ms Maria Scharnke, a young person with disability who, without consent, was picked up by teachers, carried outside the classroom and dropped on concrete and left unsupervised in an area where students stored their bags.⁵³⁹

We also heard about ‘Sam’, a young person with disability. The restrictive practices used against him were classified as an ‘adjustment’ and were used as part of a planned strategy in response to his behaviour.⁵⁴⁰ The Commissioners’ *Report of Public hearing 7* found Sam’s school had inappropriately identified restraint as a ‘reasonable adjustment’.⁵⁴¹ New South Wales accepted the finding.⁵⁴²

At Public hearing 2, ‘Inclusive education in Queensland – preliminary inquiry’, we heard from Dr Lisa Bridle, a Senior Consultant at the advocacy organisation Community Resource Unit Ltd. She said her organisation had received reports that school staff had:

- physically restrained students with disability, tied them to chairs or locked them in wheelchairs and some children had suffered bruises when they attempted to escape the restraints⁵⁴³
- confined students in spaces that were often locked and poorly supervised⁵⁴⁴
- pressured parents to increase doses of medication to modify their child’s behaviour, sometimes presenting this as a prerequisite to the child returning to school.⁵⁴⁵

Criminal justice

At Public hearing 11, ‘The experiences of people with cognitive disability in the criminal justice system’, witnesses told the Royal Commission about being secluded in their cells while in prison.⁵⁴⁶ Restrictive practices, including seclusion, were described as a ‘reactive management strategy’ typically implemented in response to aggression.⁵⁴⁷ It can become increasingly difficult to reduce or stop the use of these strategies once they are in place.⁵⁴⁸

We discuss the use of seclusion and solitary confinement in justice settings further in Volume 8, *Criminal justice and people with disability*.

We heard evidence of other restrictive practices used against two First Nations people with disability, ‘Melanie’ and ‘Winmartie’. Melanie and Winmartie were found unfit to stand trial and detained in correctional settings and forensic health facilities.

Melanie was subjected to ‘prone position restraints twice a day as matter of routine’ at a forensic health facility.⁵⁴⁹ This occurred for more than half of the time she was in seclusion. This practice contravened the New South Wales Department of Health policy.⁵⁵⁰

Winmartie was put into a restraint chair 17 times between 2012 and 2015.⁵⁵¹ There was also a long period where Winmartie spent 23 hours a day in a prison cell.⁵⁵² Winmartie’s guardian, Mr Patrick McGee, said when Winmartie was moved from one part of the prison to another, his hands and feet were shackled and connected by a chain to a belt.⁵⁵³ When Winmartie engaged in prolonged periods of head banging, prison guards would hold him down, place him in a restraint chair and inject him with a tranquiliser.⁵⁵⁴

At Public hearing 27, ‘Conditions in detention in the criminal justice system’ we heard about restrictive practices used on people with disability in justice settings. We heard about the impact of mechanical restraints – in this case, handcuffs – used on a Deaf prisoner who was rendered unable to communicate with staff.⁵⁵⁵ Other witnesses with disability spoke of the effect of prolonged use of mechanical restraints and periods of isolation during their time in criminal justice settings.⁵⁵⁶

Lane and Laylah*

‘Our role, first and foremost, is about human rights and quality of life.’

Lane is in his 40s and has Down syndrome. For many years he resided at a supported independent living home.

Laylah, a psychologist, met Lane and his parents a couple of years ago, on her first day in her ‘dream job’ working at the home.

‘They were highly distressed about the care that he was receiving,’ Laylah told the Royal Commission. ‘He had lost 10 kilos and he was on a complete liquid diet. Sometimes he had scrapes or cuts on him.’

Lane’s mother ‘was crying through the whole session’ with Laylah. She told Laylah staff were locking the door when they came to visit so they couldn’t get in. The house manager was ‘disrespectful’ to them – ‘Swearing ... Sometimes she’d call her a “bitch” or something.’

Laylah’s job was to write a behaviour support plan for Lane. A previous psychiatrist had authorised ‘chemical restraint’ for him – ‘He was on a very, very high dose of antipsychotics.’

‘But then he had lots of other restrictive practices that were not authorised.’

Laylah asked the psychiatrist about that. ‘Why he was on such a high dose of medication? Why he’s not able to eat? ... Because there was nothing in place to actually show there was a reason why he should be on a liquid diet.’

Laylah said the psychiatrist was ‘sneaky’ and ‘wasn’t helping’. When she visited Lane, she found him ‘highly sedated’.

‘He could hardly open his eyes. It seemed like he was really hungry and thirsty as well. He asked for water a few times and was told that he needed to get it himself ... They were pushing him to do all of these things himself that he wasn’t capable of, like pour boiling water into a cup.’

Laylah noticed ‘quite a few issues’ – including incidents of physical restraint – in Lane’s records.

One support worker ‘physically removed him from the toilet because he was taking too long’. Another wouldn’t let him have a bath.

‘And he sat there crying for an hour on the toilet, you know, in his own house.’

Laylah started putting together a report. She had to ‘go digging’ as staff didn’t provide information she asked for and were watching her and taking photos.

Laylah spoke with the agency of her ‘really big concerns’ about Lane’s care. The home was blocking Lane’s phone communication with his parents, which a compliance officer described as ‘a restrictive practice’.

Laylah talked to the house manager about Lane’s diet. She told her, ‘He’s starving. He’s asking for food. He’s only having milkshakes ... Most of his behaviours of concern are around wanting food.’

One of his meals was ‘like a fish milkshake’. ‘That’s something you would joke about giving someone as a punishment,’ Laylah said.

At a team meeting, she tried to teach staff ‘the basics about restrictive practices, what the legislation was’.

**‘I thought, maybe they just don’t understand neglect.
In the end, I think they did understand, but they were just
doing their own thing.’**

She warned them of the ‘serious consequences for engaging in unauthorised restrictive practices’. ‘But they were just cutting me off. They wouldn’t even let me talk.’

Three days later, the agency fired Laylah for breaching its code of conduct.

She helped Lane’s parents make a complaint to the NDIS Quality and Safeguards Commission.

‘They were elderly, they didn’t know what to do ... They said, “We didn’t know about our rights until we met you.”’

Prevalence of restrictive practice use

Data collection and reporting on the use of restrictive practices towards people with disability in Australia are poor. No robust datasets are regularly published, either at the national or state and territory level. This means the use of restrictive practices cannot be properly assessed, monitored over time or compared across settings or jurisdictions. There are gaps in data about the types of restrictive practices used and characteristics of people with disability subjected to them.

The available data on use of restrictive practices in , health, education and justice settings is examined in this section. Given the poor quality of this data, we recommend improvements to data definitions and collection methods (see Recommendation 6.39).

Disability services

The NDIS Commission collects data on the use of restrictive practices on NDIS participants by registered NDIS providers. As explained in Section 5.3, registered NDIS providers are required to report to the NDIS Commission on uses of both authorised and unauthorised restrictive practices.

NDIS providers are required to report monthly to the NDIS Commission on the use of authorised restrictive practices via an online portal, which also contains behaviour support plans.⁵⁵⁷ Separate to this, the NDIS Commission only publishes data on unauthorised restrictive practices, which it collects as a category of reportable incidents. Unauthorised restrictive practices constitute 99 per cent of the reportable incidents notified to the NDIS Commission.⁵⁵⁸ However, this does not represent the full extent of restrictive practices used in NDIS-funded disability service settings.

Unauthorised restrictive practices

The NDIS Commission initially published incorrect information for 2020–21. It has since provided an updated figure of 903,018 uses of unauthorised restrictive practices against NDIS participants in 2020–21.⁵⁵⁹

In the 2021–22 reporting period, the NDIS Commission reported 1.4 million unauthorised uses of restrictive practices against 8,830 participants.⁵⁶⁰ The rate of growth (58 per cent) has slowed compared with the sharp increase between the 2019–20 and 2020–21 reporting periods (212 per cent).⁵⁶¹ However, it is still substantial.

As with authorised restrictive practices (which we discuss below), there is a continuing upward trend in reports of the number of participants subjected to the use of unauthorised restrictive practices.⁵⁶² For the 2021–22 reporting period, 17 per cent more participants were subjected to unauthorised restrictive practices than in the previous period. The figure rose from 7,532 in 2020–21 to 8,830 participants in 2021–22.⁵⁶³ This compares with an 82 per cent increase between the 2019–20 and the 2020–21 reporting periods, from 4,140 participants to 7,532 participants.⁵⁶⁴

The NDIS Commission states this sharp increase in the reporting of unauthorised restrictive practices may be due to a number of factors, such as the expiry of transitional arrangements and growth in the number of participants accessing the NDIS. During the reporting timeframe there has also been increased understanding of reporting and compliance obligations by providers.⁵⁶⁵

Similar to trends seen in 2020–21, of the NDIS participants subjected to unauthorised restrictive practices in the 2021–22 reporting period:

- 25 per cent were subjected to one use of an unauthorised restrictive practice, 69 per cent were subjected to 100 or fewer such uses, and 8 per cent were subjected to more than 500 uses⁵⁶⁶
- 72 per cent of participants had either intellectual disability (45 per cent) or autism (27 per cent) as their primary disability⁵⁶⁷
- chemical restraints were the most frequently used form of unauthorised restrictive practice (47 per cent) followed by environmental restraints (46 per cent), mechanical restraints (5.8 per cent), physical restraints (0.8 per cent) and seclusion (0.3 per cent)⁵⁶⁸
- antipsychotics were the most frequently used medications in terms of the number of times used and the number of participants towards whom they were used⁵⁶⁹
- participants aged 14 years or under were subjected to the lowest rates of unauthorised restrictive practices (0.1 per cent for children up to the age of six years and 0.5 per cent for seven to 14-year-old participants). The highest rate occurred among 25 to 34-year-old participants (3.3 per cent).⁵⁷⁰

Participants subjected to the highest number of unauthorised restrictive practices accounted for ten percent of participants, but were subjected to more than half of the total number of unauthorised restrictive practices.⁵⁷¹

Providers are required to report each instance of an unauthorised restrictive practice as a reportable incident to the NDIS Commission.⁵⁷² This may result in a high number of unauthorised restrictive practices being reported over a period for one person. For example, if a person is administered a psychotropic medication multiple times per day as a chemical restraint, each instance would be reported separately. Similarly, the use of an environmental restraint such as multiple instances of a door being locked, would result in many reportable incidents.

Authorised restrictive practices

In an attempt to further understand the extent of restrictive practice, the Royal Commission sought and obtained information from the NDIS Commission on the use of authorised restrictive practices.

It is important to note the data recorded below reflects the authorised use of restrictive practices during a period of significant transformation in disability service provision. Authorisation and reporting of restrictive practices changed following the introduction of the NDIS. These changes have been implemented gradually across Australian jurisdictions. In some jurisdictions, transitional arrangements lapsed during the data timeframe.⁵⁷³ Additionally, states and territories transitioning to the NDIS means there is no robust data to demonstrate the use of unauthorised restrictive practices over time. For these reasons, caution must be used when drawing conclusions from the following data.

The NDIS Commissioner provided additional data at Public hearing 32.⁵⁷⁴ The data distinguished between routine and PRN or 'as needed', uses of restrictive practices, and the type of restrictive practice. These practices included seclusion, chemical, mechanical, physical and environmental restraint.

However, the data was not disaggregated by the setting in which a restrictive practice was used. Ms Mackey stated that:

while behaviour support plans identify the circumstances in which a restrictive practice can be implemented, implementing providers are not required to report the setting in which they used a restrictive practice, either generally or for each individual use.⁵⁷⁵

Ms Mackey explained this is because:

For some participants, a restrictive practice may be used in different settings throughout a day or week. For example, a participant may require PRN medication to assist with mood stabilisation, and this may be used in the participant's home, in a day program and/or the community depending upon the participant's circumstances and the settings in which the participant receives NDIS supports.⁵⁷⁶

In the 2020–21 reporting period, there were 3.68 million uses of authorised restrictive practices and 7,284 NDIS participants subjected to them. By comparison, in the 2021–22 reporting period, there were 5.58 million total uses of authorised restrictive practices and 8,685 NDIS participants subjected to them.⁵⁷⁷ Tables 6.5.1 and 6.5.2 provide further detail. These figures demonstrate a substantial (52 per cent) increase in the use of authorised restrictive practices between 2020–21 and 2021–22.

Table 6.5.1: Routine and PRN uses of authorised restrictive practices under behaviour support plans lodged with the NDIS Commission and number of participants affected from 1 July 2020 to 30 June 2021

Administration type	Occasions of use	Number of participants
Routine use of restrictive practice	3,525,375	6,878
PRN use of restrictive practice	150,099	1,785
Data not available	1,658	11
Total	3,677,132	7,284^a

^a Some participants are subjected to more than one type of restrictive practice under their behaviour support plan. In this table, those participants are counted once for each applicable restrictive practice type, but they are only counted once for the total number of participants. The total number of participants is therefore less than the sum of participants for each type of restrictive practice.

Source: Exhibit 32-008, 'Statement of Tracy Mackey', 3 February 2023, at [135].

Table 6.5.2 Routine and PRN uses of authorised restrictive practices under behaviour support plans lodged with the NDIS Commission and number of participants affected from 1 July 2021 to 30 June 2022

Administration type	Occasions of use	Number of participants
Routine use of restrictive practice	5,375,935	8,242
PRN use of restrictive practice	202,082	2,197
Data not available	1,122	12
Total	5,579,139	8,685^a

^a Some participants are subjected to more than one type of restrictive practice under their behaviour support plan. In this table, those participants are counted once for each applicable restrictive practice type, but they are only counted once for the total number of participants. The total number of participants is therefore less than the sum of participants for each type of restrictive practice.

Source: Exhibit 32-008, 'Statement of Tracy Mackey', 3 February 2023, at [135].

Ms Mackey was asked to explain this increase in the use of authorised restrictive practices. She said that during 2020–21 to 2021–22:⁵⁷⁸

- All states and territories transitioned to the NDIS. This meant there was a growth in participant numbers in real terms. Therefore, the number of people subjected to restrictive practices as part of a behaviour support plan increased.
- The number of behaviour support plans lodged increased, resulting in the NDIS Commission having greater visibility of authorised uses of restrictive practices.
- There was a higher level of compliance from providers in reporting restrictive practices.

Ms Mackey acknowledged the increase appeared to be ‘quite significant’, but this was not necessarily attributable to greater use of authorised restrictive practices. Rather it was to do with ‘an increase in number of participants and increase in the reporting of those’.⁵⁷⁹ During this period, Western Australia became the final state to participate in the NDIS, with the roll out in that state completed in July 2020.

Ms Mackey also provided data on the average number of times a restrictive practice was used on a NDIS participant. For example, in the 2021–22 reporting period, there was an average of 642 authorised uses of a restrictive practice per participant.⁵⁸⁰ This increased by 27 per cent from 2020–21, when there was an average of 505 authorised uses of a restrictive practice per participant.

While the number of NDIS participants subjected to authorised restrictive practices increased each year, the number of ‘occasions of use’ appears to have increased at an even faster rate. This drove the increase in the average use per participant, suggesting the experience of NDIS participants subjected to authorised restrictive practices is probably becoming more intense over time.

Ms Mackey explained some participants are subjected to multiple types of restrictive practices.⁵⁸¹ For example, chemical restraints might be administered three or more times per day.⁵⁸² Ms Mackey acknowledged ‘the volume of restrictive practices can be very significant for one individual’.⁵⁸³

In the 2021–22 reporting period, chemical restraints were used more than other forms of authorised restrictive practices on NDIS participants (2.9 million occasions of use). This was followed by environmental restraints (2.3 million occasions of use) and mechanical restraints (279,402 occasions of use).⁵⁸⁴

The participants who were subjected to chemical restraints experienced an average of 539 uses per participant, equivalent to almost 1.5 uses per day. Despite this, from 2020–21 to 2021–22, the sharpest increase was in the use of environmental restraints (60 per cent), followed by chemical restraints (49 per cent) and mechanical restraints (36 per cent). Tables 6.5.3 and 6.5.4 explain this further.

Table 6.5.3: Types of restrictive practices used under behaviour support plans lodged with the NDIS Commission and the number of participants affected from 1 July 2020 to 30 June 2021

Restrictive practice type	Occasions of use	Number of participants
Seclusion	19,147	189
Chemical restraint	1,969,002	4,518
Mechanical restraint	205,401	1,043
Physical restraint	52,025	548
Environmental restraint	1,431,557	4,341
Data not available	0	0
Total	3,677,132	7,284^a

^a Some participants are subjected to more than one type of restrictive practice under their behaviour support plan. In this table, those participants are counted once for each applicable restrictive practice type, but they are only counted once for the total number of participants. The total number of participants is therefore less than the sum of participants for each type of restrictive practice.

Source: Exhibit 32-008, 'Statement of Tracy Mackey', 3 February 2023, at [136].

Table 6.5.4: Types of restrictive practices used under behaviour support plans lodged with the NDIS Commission and the number of participants affected from 1 July 2021 to 30 June 2022

Restrictive practice type	Occasions of use	Number of participants
Seclusion	24,830	241
Chemical restraint	2,924,506	5,430
Mechanical restraint	279,402	1,266
Physical restraint	66,778	627
Environmental restraint	2,283,562	5,367
Data not available	61	1
Total	5,579,139	8,685^a

^a Some participants are subjected to more than one type of restrictive practice under their behaviour support plan. In this table, those participants are counted once for each applicable restrictive practice type, but they are only counted once for the total number of participants. The total number of participants is therefore less than the sum of participants for each type of restrictive practice.

Source: Exhibit 32-008, 'Statement of Tracy Mackey', 3 February 2023, at [136].

All types of restrictive practices, except for physical restraints, were more likely to be used routinely. In both the 2020–21 and 2021–22 reporting periods, routine use of physical restraint was surpassed by PRN use, as seen in Tables 6.5.5 and 6.5.6.

Table 6.5.5: Routine and PRN uses of restrictive practices under behaviour support plans lodged with the NDIS Commission from 1 July 2020 to 30 June 2021

Restrictive practice type	Routine	PRN	Data not available
Seclusion	13,972	5,175	0
Chemical restraint	1,916,933	52,069	0
Mechanical restraint	180,578	24,823	0
Physical restraint	20,186	31,443	396
Environmental restraint	1,393,706	36,589	1,262
Data not available	0	0	0
Total	3,525,375	150,099	1,658

Source: Exhibit 32-008, 'Statement of Tracy Mackey', 3 February 2023, at [137].

Table 6.5.6: Routine and PRN uses of restrictive practices under behaviour support plans lodged with the NDIS Commission from 1 July 2021 to 30 June 2022

Restrictive practice type	Routine	PRN	Data not available
Seclusion	17,073	7,757	0
Chemical restraint	2,855,634	68,872	0
Mechanical restraint	249,350	29,993	59
Physical restraint	21,371	45,354	53
Environmental restraint	2,232,507	50,106	949
Data not available	0	0	61
Total	5,375,935	202,082	1122

Source: Exhibit 32-008, 'Statement of Tracy Mackey', 3 February 2023, at [137].

The data shows a substantial number of NDIS participants are subjected to ongoing use of authorised restrictive practices, often multiple times per day. We accept the increase over the two-year period was driven in part by improved understanding of reporting requirements and the

full-scheme rollout of the NDIS across all states and territories. But the data demonstrates the need for change to reduce the use of authorised restrictive practices on people with disability, particularly NDIS participants.

Health settings

The Australian Institute of Health and Welfare (AIHW) publishes data on some forms of restrictive practices used in mental health care as a key performance indicator for Australian Public Mental Health Services. The data covers seclusion and physical and mechanical restraints.⁵⁸⁵ However, it is not broken down by disability status. There is also no detail on the circumstances leading up to the use of the restrictive practices.

The following results for 2020–21 indicate:⁵⁸⁶

- 7.3 seclusion events per 1,000 bed days in public acute mental health hospital services. This is a decrease from a rate of 8.1 events in the previous year and from 15.6 during 2008–09, when data coverage began. Over the last five years (2016–17 to 2020–21) there has been an average annual decrease in the national seclusion rate of -0.4 per cent.
- 11.6 physical restraint events per 1,000 bed days. The rate of physical restraint has remained between 10.1 and 11.6 since 2015–16 when data coverage began.
- 0.7 mechanical restraint events per 1,000 bed days. The rate of mechanical restraint was 1.7 during 2015–16 when data coverage began. Over the last five years (2016–17 to 2020–21) there has been an average annual decrease in the mechanical restraint rate of -8.2 per cent.

This data is only related to the use of restrictive practices in acute mental health care settings in Australian public hospitals. It does not cover rehabilitation or extended care settings, general health settings or forensic health settings.

As the data is not disaggregated by disability status we cannot determine the extent to which seclusion and physical and mechanical restraints are used against people with disability in mental health settings and we cannot see how this has changed over time. Therefore, we do not know if people with disability are benefiting from overall reductions in the use of restrictive practices in mental health settings or whether more targeted strategies are needed.

As we found from Public hearing 6, in health settings Australia does not collect reliable national data on:⁵⁸⁷

- the extent to which psychotropic drugs are prescribed for people with cognitive disability
- the purposes for which psychotropic medication is prescribed for people with cognitive disability, for example, whether the prescription is for the treatment of a diagnosed medical illness or to respond to behaviours of concern.

The NDIS Commission is seeking to address this data gap through the data linkage study, *Psychotropic use in people with disability in Australia*, which its Behaviour Support team commenced in August 2022.⁵⁸⁸ This is discussed further in Section 5.6.

Education settings

State and territory governments do not report on the use of restrictive practices against students in public schools. We requested centrally held data from state and territory education departments, specifically about the number of complaints they received about the use of restrictive practices between 2015 and 2020. We also requested the number of reported incidents of the use of restrictive practices against both students with disability and those without disability. Most jurisdictions either did not provide complete data or reported numbers too low for analysis.⁵⁸⁹

We have been unable to rely on this data to quantify the extent to which restrictive practices are used against students with disability at school. This is due to apparent underreporting, small sample sizes and incomplete data provided by states and territories. The need for improved data collection and reporting is further discussed in Section 5.8 and is also addressed in Volume 7, *Inclusive education, employment and housing*.

Our analysis mirrors the CRPD Committee's concerns about the lack of national disaggregated data on students with disability in Australia, including on the use of restrictive practices.⁵⁹⁰ The CRPD Committee noted the lack of data on rates of use of restrictive practices against students with disability and recommended the Australian Government expand the collection of data.⁵⁹¹

Similarly, past reports and inquiries about education have called for improvements to data collection about the experiences of students with disability.⁵⁹²

In New South Wales, the exposure draft of the Persons with Disability (Regulation of Restrictive Practices) Bill 2021 proposes that data on the use of restrictive practices in government sector agencies (which would include public schools) be submitted to the Ageing and Disability Commission.⁵⁹³ However, as we have recorded, it is not clear if the Bill in its current form will be progressed and if so, when.

Justice settings

There is little published data about use of restrictive practices in justice settings. A report commissioned by the Royal Commission shows prisons do not routinely collect or publish data on the use of restraints, including seclusion.⁵⁹⁴ There is also a notable gap in data recording complaints concerning people with disability who have been subjected to restrictive practices in prisons.⁵⁹⁵

Two one-off inquiry reports provide limited data for the use of seclusion in youth detention. First, the Inspector of Custodial Services reported 4,401 episodes of confinement to a place as punishment during 2019–20 across six New South Wales youth detention centres.⁵⁹⁶ These episodes made up 70 per cent of all punishments administered during this period.⁵⁹⁷ Second, an inquiry into the use of isolation, separation and lockdowns in the Victorian youth justice system, conducted by the Commission for Children and Young People, recorded 4,817 separate episodes of isolation between February 2015 and July 2016.⁵⁹⁸

Despite the prevalence of children and young people with disability in youth detention centres, neither inquiry recorded the number of individuals who identified as having disability. Therefore, we could not determine the proportion of seclusion incidents involving young people with disability.⁵⁹⁹

Systemic drivers of restrictive practices

A range of systemic factors, across NDIS, education, justice and health settings, contribute to the use of restrictive practices.

Disability services

Group home environments

A number of factors contribute to the regular use of restrictive practices in some group homes, including a lack of person-centred approaches, incompatibility of residents and workforce issues. In the Commissioners' *Report of Public hearing 6*, we found environmental factors, including lack of choice in accommodation, unsuitable living arrangements and social isolation increased the incidence of behaviours of concern. Living in these conditions can have long-term effects on the health and wellbeing of people with cognitive disability.⁶⁰⁰

Ms McLean told us that from the moment her son was moved into the group home, he was in a restricted environment where doors, windows and cupboards were locked. She said he immediately responded by destroying his bedroom and by finding ways to escape and walk long distances from the home.⁶⁰¹ Ms McLean said she was also aware of other individuals living in locked environments with little contact with their families and the outside world.⁶⁰²

In Public hearing 3, Dr Spivakovsky said that the strictly regulated environment in group homes gives rise to the 'self-perpetuating fallacy of restrictive practices'.⁶⁰³ In her research she has found the frustration residents feel because of their disempowerment is often communicated in forms that are labelled 'behaviours of concern'.⁶⁰⁴ These behaviours are then used to justify restrictive practices.⁶⁰⁵

Ms Forbes from VALiD also gave evidence about what happens when people who are incompatible are forced to live together. Often conflict between residents will be met with a 'clinical response', where a psychologist will write a behaviour support plan, staff will be required to report on incidents and restrictive practices are used.⁶⁰⁶ Ms Forbes said that she has repeatedly seen behaviours go away when a person moves into their own home.⁶⁰⁷

Similarly, at Public hearing 32, Ms Hayley Dean, CEO of Melba Support Services Inc, told us that when people who display behaviours of concern had the opportunity to live on their own or with people they choose, the behaviour reduced.⁶⁰⁸

We acknowledge the experiences of people in disability-specific accommodation settings are not confined to group homes and probably extend to other supported accommodation. We also acknowledge that these experiences are not universal in group homes.

The *Pathway to elimination* report supports the evidence we heard in public hearings about the use of restrictive practices in disability-specific settings. The researchers considered the systemic drivers of the use of restrictive practices in residential settings including group homes. They found the lack of choice and autonomy for people with disability contributes to the increased use of restrictive practices in these settings.⁶⁰⁹

We discuss group homes more generally and reforms needed to address these issues in Volume 7 and Volume 10.

Support staff require education and training

... the history of restrictive practice and it being normalised in the disability sector as something that you just do and it's just a tool and that is really still ever present and widespread in many spaces, even with NDIS coming into the picture ... in many group homes I've seen staff members and even house supervisors just really not ... it's just not computing in their head that what they're doing is restrictive practice ...⁶¹⁰

At Public hearing 3, Mr Arthur Rogers, the Victorian Disability Services Commissioner identified a culture of passive acceptance of the use of restrictive practices in group homes. Mr Rogers said:

it's about the culture of the home, where staff think it's okay to do things. They don't realise [they are using] a restraint. In fact it clearly is a restraint of someone's freedoms and we note that basically it's about sort of ignorance to that or acceptance somehow of the culture and the process of the house that restraints are okay.⁶¹¹

Mr Rogers told us about a person with disability being prevented from leaving their room because of concerns of compatibility with other residents. He said that in group homes, restrictions like this 'seem to be acceptable' but 'when they come to our attention we clearly point out they're not'.⁶¹²

Professor Keith McVilly at Public Hearing 6 explained how lack of resourcing and training can contribute to the use of restrictive practices:

[u]nder resourcing in the disability sector where poorly trained disability support workers are either left on their own, or with very few people they can refer to for support or advice when behavioural situations are emerging ... leaves them with the only alternative being the use of medication.⁶¹³

Similarly, witnesses at Public hearing 20, 'Preventing and responding to violence, abuse, neglect and exploitation in disability services (two case studies)', told us about issues at a Life Without Barriers group home in Melbourne, including problems concerning staffing levels, managing residents' behaviours of concern, responding to resident violence and giving staff enough time to do critical paperwork during their shifts.⁶¹⁴ The Commissioners' *Report of Public hearing 20* found there was inadequate support and leadership from Life Without Barriers' management for disability support workers at the Melbourne house.⁶¹⁵

We discuss education and training of support staff further in Volume 10.

Behaviour support practices underutilised

I would like to see a greater emphasis on behaviour support ...
My hope for the future is that governments and care organisations
learn that the power of [behaviour support] benefits everybody...⁶¹⁶

According to the NDIS Commission, positive behaviour support is about 'creating individualised strategies for people with disability that are responsive to the person's needs, in a way that reduces and eliminates the need for the use of regulated restrictive practices'.⁶¹⁷

[Positive behaviour support] focuses on evidence-based strategies and person-centred supports that address the needs of the person with disability and the underlying causes of behaviours of concern, while safeguarding the dignity and quality of life of people with disability who require specialist behaviour support.⁶¹⁸

At Public hearing 6, Professor Dowse gave evidence that positive behaviour support has 'been developed in Australia over the last 20 years, and is now recognised as best practice for responding to behaviours of concern'.⁶¹⁹

Professor Dowse's view was reflected in evidence from Ms Joyce-Lyn Smith, Clinical Director of a business that provides support services to people with disability. She stated, 'there is sufficient evidence-based research that shows that positive behaviour support and capacity skills building is an effective alternative to restrictive practice, including chemical restraint'.⁶²⁰ However, Ms Smith also noted it is often the behaviours of the people around the person with disability that

need to be changed. She believed this can be achieved through developing behaviour support strategies for those people rather than focusing on changing the behaviours of the person with disability.⁶²¹

In the report of Public hearing 6, Commissioners found positive behaviour support reduces the incidence of behaviours of concern among people with cognitive disability and the use of psychotropic drugs as a chemical restraint. This depends, however, on the strategy being designed and implemented carefully.⁶²²

Witnesses in other public hearings also spoke of the direct link between the use of positive behaviour support strategies by support workers and the prevalence of restrictive practices.

At Public hearing 13, 'Preventing and responding to violence, abuse, neglect and exploitation in disability services (a Case Study)', 'Sophia' described how support workers play a key role in whether her son 'Carl', a person with disability, has a good or bad day.⁶²³ According to Sophia, if support workers spend time with Carl and try to understand what he is saying, he will feel heard and that somebody cares. If this does not happen, Carl is more likely to resort to behaviours of concern.⁶²⁴ Sophia thought that incidents could be prevented if Carl had more interaction with support workers. While a lot of resources were spent on Carl's behaviour support plans, she sometimes wondered if support workers even read the plans.⁶²⁵

A similar view was expressed in Public hearing 20 by 'Greg' and 'Michelle', parents of a person with disability who was living in a home managed by Life Without Barriers. They echoed concerns about the inadequacy of support workers' ongoing training and ability to recognise and respond to people with disability with complex support needs and 'escalating behaviours'.⁶²⁶ Michelle said:

these are the people who are working with adults with disabilities. They should know. This is simple. This is A, B, C training. They should have had this right from the beginning. When they start working there, they should have been familiarised with the behaviour plan, given the profile of the person ... But we felt there was nothing like that.⁶²⁷

At Public hearing 3, AAG, the mother of a person with disability, AAF, said when AAF is cared for 'properly, and managed consistently with kindness, understanding and positive behaviour strategies', she 'really flourishes'.⁶²⁸ But when staff do not follow her daughter's routine and impose consequences for behaviour by way of either rewards or a punishment chart, her daughter 'can't cope'.⁶²⁹

Ms Christine Barbuto, a Community Visitor, described how casual staff often do not have time to read a behaviour support plan, meaning they are not always familiar with the individuals or their needs. This compromises the quality of support provided, leading to impacts on individuals.⁶³⁰

We discuss support planning, including behaviour support plans, in greater detail in Volume 10. Volume 10 also examines broader structural and workforce factors that contribute to the poor quality and implementation of support plans, and makes recommendations to address these issues.

Health settings

People with intellectual disability or cognitive impairment can experience trauma and distress when they undergo health procedures or treatment, whether in clinical environments, the community or hospital. So-called ‘challenging’ behaviour induced by stress can be extremely detrimental to good health care, for example if treatment has to be postponed or abandoned. Repeated distressing experiences can intensify this stress and can lead people with disability and their families to lose trust in the health system and fear further interactions.⁶³¹

Several witnesses gave evidence about the impact of the sensory environment on a person with intellectual disability or autism. Dr Jacqueline Small, a developmental paediatrician with over 32 years of clinical experience, said attending a hospital emergency department can be a ‘stressful, anxiety-provoking situation’ for anyone.⁶³² For a person with intellectual disability it can lead to ‘increased challenging behaviours or distress’.⁶³³ ‘Challenging behaviours’ can include resisting treatment and attempting to remove medical devices, such as cannulas.⁶³⁴ This can be detrimental to the person’s care, particularly if it prevents treatment, and can encourage staff, carers or support workers to use restrictive practices.⁶³⁵

Repeated distressing experiences in hospitals and other clinical settings can result in an accumulation of trauma. Ms Browne said it became increasingly difficult for her son to have a routine blood test, because the procedure was generally not well managed. Clinical adaptations were not made for Finlay’s distress and the experience became increasingly traumatic for him.⁶³⁶

The Victorian Royal Commission reported on the wide range of factors contributing to the use of seclusion and restraint in mental health settings, including the physical environment and concerns about the safety and wellbeing of staff.⁶³⁷

We discuss reforms to the health system, including building the capability of the health workforce to understand and respond to the different needs of people with disability, in Chapter 4, ‘Health care and treatment’.

Education

Evidence at Public hearings 2 and 7 suggests educators can mischaracterise ‘behaviours of concern’ as a student with disability being wilfully disruptive or naughty. The educators might then respond punitively, rather than attempt to understand or address the underlying cause of the behaviours.

Dr Bridle said users of Community Resource Unit Ltd services had reported a ‘particular failure’ on the part of schools to understand and respond where behaviours of concern are a form of communication or a response to an unmet need.⁶³⁸

Professor Linda Graham is a Professor in the School of Early Childhood and Inclusive Education and the Director of the Centre for Inclusive Education at Queensland University

of Technology. She told the Royal Commission her research found educators had assumed imposing discipline for undesirable behaviour would lead to behavioural change.⁶³⁹ Underpinning this assumption is the belief ‘misbehaviour’ results from conscious decision-making, not poor self-regulation and inability to consider possible consequences before acting.⁶⁴⁰

This belief was consistent with evidence from AAA and AAC during Public hearing 2. They described how teachers confiscated tools their children needed to help them concentrate or to regulate their behaviour.⁶⁴¹ Dr Bridle said her clients had reported similar issues. She said many teachers incorrectly viewed these tools as ‘rewards’ to be earned or withheld in response to misbehaviour.⁶⁴²

This evidence demonstrates a need for further training and support so teachers understand and respond appropriately to ‘behaviours of concern’, thereby avoiding the use of restrictive practices. Dr Bridle said her experience suggested many teachers had a poor understanding of either their legal obligations or the complexity and causes of certain behaviours of children with disability.⁶⁴³ Mrs Deborah Wilson, the CEO of Independent Advocacy North Queensland, said school staff were not told about the importance of positive behaviour support plans in mitigating ‘behaviours of concern’.⁶⁴⁴

We discuss the need for, and make recommendations on, workforce capabilities, expertise and development for teachers in Volume 7.

Criminal justice and forensic mental health settings

The use of seclusion can become entrenched

At Public hearing 11, we heard from Dr David Manchester and Professor James Ogloff, registered psychologists with experience reviewing forensic disability service systems. They explained that long-term seclusion can become a pattern for people with complex needs in correctional and forensic facilities, even when its harmful nature is recognised.⁶⁴⁵

Dr Manchester gave evidence about Melanie, a First Nations woman found unfit to be tried for serious acts of violence. She was detained at a forensic hospital.⁶⁴⁶ In this context, Dr Manchester described restrictive practices such as seclusion as a ‘reactive management strategy’, typically implemented in response to aggression. Restrictive practices are generally seen as short-term measures to manage risk, rather than ‘therapeutic endeavours that would be akin to treatment that help a person to cope better in the future’.⁶⁴⁷ Dr Manchester explained that restrictive practices like seclusion reduce the risk staff will come into contact with an aggressive or unsettled patient. Because restrictive practices have these apparent benefits, they can become increasingly routine once in place. This can trigger further aggression by the person in seclusion and lead to an escalating cycle of seclusion in response to aggression.⁶⁴⁸

Professor Ogloff said once people become entrenched in a pattern of prolonged seclusion, ‘it’s very, very difficult to change that, and particularly when we have limited opportunities for

something truly different'.⁶⁴⁹ He said if efforts to move a person from seclusion are not made, this form of management can become a 'rut'. A 'collective learned helplessness' about changing the situation can develop for both the person subject to seclusion and those responsible for their care.⁶⁵⁰

This was demonstrated in evidence about Melanie, who was held in prolonged seclusion at the NSW Forensic Hospital. An external investigation of seclusion practices at the hospital concluded it was 'widely recognised within the different professional groups interviewed that the use of long-term seclusion had become part of an unhelpful culture'.⁶⁵¹ The report found systemic issues contributed to this culture, including:⁶⁵²

- fear and frustration among frontline staff about violence directed at them and a perceived lack of response by the authorities
- difficulties in recruiting suitable staff leading to burnout and staff shortages
- problematic physical and social environments for patients.

The investigator recorded:

all professionals we interviewed acknowledged that it was less than optimal care to keep these individuals in seclusion indefinitely and that long-term seclusion was an unpleasant experience for anyone subjected to it. However, many professionals reported a feeling of helplessness.⁶⁵³

The *Pathway to elimination* report study considered a review of the international literature on restrictive practices in forensic mental health settings.⁶⁵⁴ This review found the use and duration of seclusion, and the use of involuntary medication, were higher in secure mental health settings than in general mental health settings.⁶⁵⁵

Understaffing and inexperience

At Public hearing 11, Dr Andrew Ellis, Clinical Director at the NSW Forensic Hospital, told the Royal Commission the 'first and greatest' challenge to moving Melanie from seclusion was 'the significant shortfall in staffing ... across all disciplines'.⁶⁵⁶ Dr Ellis explained this shortfall meant staff 'were spread thinly covering vacancies', meaning it was not possible to develop a core team to work with Melanie.⁶⁵⁷

Similarly, Mr Brett Holmes, the General Secretary of the NSW Nurses and Midwives Association, described the problems of understaffing coupled with inexperience in forensic hospitals. He said this contributed to a situation where nurses were unable to move patients who had been violent out of seclusion. The ongoing staffing shortage the NSW Nurses and Midwives Association faced at the NSW Forensic Hospital meant 'almost 30 full time equivalent vacancies' had to be replaced by casual or agency staff or staff working overtime.⁶⁵⁸ Mr Holmes agreed it was possible to balance obligations to workers with a patient's right to be treated in the least restrictive environment possible. However, this required adequate numbers of appropriately trained and highly skilled staff working in a suitable environment.⁶⁵⁹

In Volume 8, we discuss reforms to the criminal justice system to prevent the overuse of seclusion and restraint because of staffing shortfalls or people being subject to a detention order without a maximum term.

5.5. Stronger legal frameworks

Calls for reform by past Royal Commissions

Recent royal commissions have recommended reforms to improve the regulation of restrictive practices. Their reports have considered restrictive practices in the contexts of mental health, child protection, juvenile justice and aged care.

The Victorian Royal Commission examined seclusion and restraint in mental health services. Some witnesses argued that ‘prohibiting the use of seclusion and restraint through legislation is the only approach that will eliminate seclusion and restraint’.⁶⁶⁰ Professor Penelope Weller, Professor of the Centre for Business and Human Rights at RMIT University, appeared before the Victorian Royal Commission in a personal capacity. Professor Weller observed, ‘[s]ome commentators argue that the inclusion of the current framework of safeguards has legitimised and encouraged the use of such restrictive practices’.⁶⁶¹

The Victorian Royal Commission stated ‘this indicates a view that, as long as the option to seclude or restrain a consumer remains available, staff will continue to use these practices rather than find alternatives’.⁶⁶² However, the Victorian Royal Commission concluded that the policy goal of eliminating forms of restrictive practices is achievable without a wholesale prohibition on their use. The Victorian Royal Commission proposed a policy design approach, which would support services to understand the drivers of the use of restrictive practices in specific settings and reduce their use over time.⁶⁶³ The Victorian Royal Commission characterised a redesign of the regulation of restrictive practices as ‘protection, not permission’.⁶⁶⁴

The Victorian Royal Commission acknowledged ‘there may always need to be the ability to seclude or restrain in extreme emergencies’.⁶⁶⁵ However, ‘a high threshold for this should be set, and restrictive practices should be considered a deviation in practice rather than a necessary protection’.⁶⁶⁶ The Victorian Royal Commission recommended the Victorian Government ‘work toward eliminating seclusion and restraint as acceptable practice in mental health services and wellbeing delivery within 10 years’.⁶⁶⁷

The Royal Commission into the Protection and Detention of Children in the Northern Territory (Northern Territory Royal Commission) acknowledged ‘within the secure environment of a prison or detention centre, maintaining security or the safety of detainees by the use of force may, on occasion, be necessary’.⁶⁶⁸ The Northern Territory Royal Commission also referred to the human rights standard in article 64 of the *United Nations Rules for the Protection of Juveniles Deprived of their Liberty*. Article 64 provides that:

instruments of restraint and force can only be used in exceptional cases, where all other control methods have been exhausted and failed, and only as explicitly authorized and specified by law and regulation. They should not cause humiliation or degradation, and should be used restrictively and only for the shortest possible period of time.⁶⁶⁹

The Northern Territory Royal Commission made findings about the use of isolation on detainees at the Don Dale Youth Detention Centre being potentially inconsistent with numerous human rights standards⁶⁷⁰ and about the improper use of restraint.⁶⁷¹ The Northern Territory Royal Commission recommended legislative changes to ensure:

- restraints are only used to protect a detainee from self-harm, protect the safety of another person or 'protect against serious damage to property and an emergency situation exists'⁶⁷²
- separation from other detainees only occurs in limited circumstances, including where this is reasonably necessary either to protect the safety of another person or property or to restore order at the detention facility, but only after all reasonable behavioural or therapeutic options have been attempted and no other course is reasonably available or practical.⁶⁷³

The Northern Territory Government responded by amending the *Youth Justice Act 2005* (NT) in 2018.⁶⁷⁴ The key amendments included:

- prohibiting the use of force, restraints and isolation for the purposes of disciplining a child or young person in detention⁶⁷⁵
- clearly defining and limiting the circumstances upon when and how the use of force and restraints can be used towards young people in detention⁶⁷⁶
- prohibiting the isolation of young people for the purpose of punishment or behaviour management, and clarifying that young people may only be separated in very specific circumstances with access to safeguards.⁶⁷⁷

The Royal Commission into Aged Care Quality and Safety (Aged Care Royal Commission) concluded the 'regulation of restrictive practices [in aged care] should be informed by respecting and supporting people's rights, dignity and personal autonomy, while providing clarity about the circumstances in which ... restrictive practices may be authorised'.⁶⁷⁸

The Aged Care Royal Commission recommended:

restrictive practices should only be used in relation to a person when recommended by an independent expert, and where alternative strategies to meet the person's needs have been tried and found to be unsuccessful. Any exception that applies if a restrictive practice is necessary in an emergency should only apply for a short period, such as to prevent a person from imminent risk of significant harm.⁶⁷⁹

In response, the Australian Government amended the *Quality of Care Principles 2014* (Cth)⁶⁸⁰ to require aged care providers to satisfy several conditions before and during the use of any restrictive practice outside of emergency situations. These conditions include:

-
- documenting the alternatives to restrictive practices that have been considered and used⁶⁸¹
 - monitoring the person on whom restrictive practices are used for signs of distress or harm, side effects, adverse events, and changes in wellbeing, independent functions or ability to undertake activities of daily living⁶⁸²
 - reviewing the necessity and effectiveness of the restrictive practice⁶⁸³
 - to the extent possible, making changes to the person's environment to reduce or remove the need for the use of the restrictive practice.⁶⁸⁴

The Aged Care Royal Commission also recommended that restrictive practices should only be used 'in accordance with relevant State or Territory laws and with the documented informed consent of the person receiving care or someone authorised by law to give consent on that person's behalf'.⁶⁸⁵

Amendments to the *Quality of Care Principles 2014* (Cth) in response to this recommendation aimed to 'provide greater clarity on informed consent for the use of restrictive practices where consumers lack the capacity to consent on their own behalf and there is no explicit legal avenue under state [or] territory laws for a restrictive practices substitute decision-maker to be appointed'.⁶⁸⁶ The amended *Quality of Care Principles 2014* (Cth) set out a hierarchy of persons or bodies who can give consent where restrictive practices are necessary and an aged care recipient is deemed unable to provide consent or a substitute decision-maker has not been, or cannot be, appointed.⁶⁸⁷ The hierarchy will remain in place until 1 December 2024, with a replacement mechanism for consent to be included in a new Aged Care Act.⁶⁸⁸

The Queensland Public Guardian undertook to monitor these reforms to the *Aged Care Act 1997* (Cth) and *Quality of Care Principles 2014* (Cth), and 'any subsequent impacts on guardianship appointments made by QCAT relating to restrictive practices in residential aged care'.⁶⁸⁹ This data was not available at the time of writing.

We discuss consent in the context of restrictive practices and the impact of reforms following the Aged Care Royal Commission further in the next section.

Authorisation, review and oversight

In Section 5.3 we noted the patchwork of regulation of restrictive practices across Australian jurisdictions that can lead to uncertainty and unequal protection for people with disability. In this section, we make recommendations intended to bring about greater uniformity and clarity in regulatory structures.

Towards consistency of authorisation, review and oversight

Reform is needed to improve the processes for authorisation, review and oversight of restrictive practices.

States and territories should have legal frameworks in place providing that a person with disability cannot be subjected to restrictive practices, except in accordance with procedures for authorisation, review and oversight established by law. Ensuring these legal frameworks are in place may involve developing new legal frameworks or amending existing ones.

Processes for authorisation of use should be as clear and precise as possible, and the legal consequences of unlawful use spelled out. People with disability and their families and supporters must be able to understand how restrictive practices can be used and what legal avenues for recourse are open should the laws be breached.

The use of restrictive practices should be independently overseen and monitored and authorisation decisions should be subject to independent review. The legal framework ideally should provide remedies for the unlawful use of restrictive practices.

As we have explained in Section 5.3, not all states and territories have legislation governing the use of restrictive practices. The ‘appropriate legal framework’ can comprise a combination of legislation, regulations, rules, practice directions and policies and procedures.

The legal framework should apply to any person or entity from a relevant sector with power to authorise the use of or use restrictive practices on people with disability. This includes those from the disability, health, education and justice sectors.

The legal framework in each state and territory should be based on the following:

- Restrictive practices should only be authorised and used:
 - as a last resort, in response to a serious risk of harm to the person with disability or others and only after other strategies, including supported decision-making, have been explored and applied
 - as the least restrictive response possible to ensure the safety of the person with disability or others
 - to the extent necessary to reduce the risk of harm and proportionate to the potential negative consequences from the use of restrictive practices
 - for the shortest time possible.
- Decisions to authorise restrictive practices should be subject to independent review.
- The use of restrictive practices should be subject to independent oversight and monitoring.

We recognise restrictive practices are used in a variety of settings and situations. For this reason, the requirements we have set out for legal frameworks are intended to apply generally. The aim is for all state and territory legal frameworks on restrictive practices to include these requirements, appropriately adapted to sector-specific requirements.

Authorisation and use

Restrictive practices should only be used in limited circumstances

The requirements for authorisation and use of restrictive practices we have proposed align with the approach in the 2014 National Framework. The National Framework states:

Restrictive practices should occur only in very limited and specific circumstances, as a last resort and utilising the least restrictive practice and for the shortest period of time possible under the circumstances. Restrictive practices should only be used where they are proportionate and justified in order to protect the rights or safety of the person or others.⁶⁹⁰

These considerations were adapted in the *NDIS Restrictive Practices Rules*. They provide that the registration of a specialist behaviour support provider is subject to the condition that, if a specialist behaviour support provider develops or reviews a behaviour support plan for a person with disability that contains the use of a regulated restrictive practice, the regulated restrictive practice must:⁶⁹¹

- be used only as a last resort in response to risk of harm to the person with disability or to others, and after the provider has explored and applied evidence-based, person-centred and proactive strategies
- be the least restrictive response possible in the circumstances to ensure the safety of the person or of others
- reduce the risk of harm to the person with disability or to others
- be in proportion to the potential negative consequence or risk of harm
- be used for the shortest possible time to ensure the safety of the person with disability or others.

Our recommended requirements for authorisation and use of restrictive practices incorporate many of these elements.

They also align with recommendations of other recent royal commissions, that restrictive practices should be used in limited circumstances, as a last resort and in the least restrictive way. In particular, they reflect the Victorian Royal Commission's position that 'a high threshold ... should be set' for the use of restrictive practices.⁶⁹²

Supported decision-making and the issue of informed consent

We consider supported decision-making has an important role to play in preventing the use of restrictive practices and ensuring they are only used as a last resort across all settings. Supported decision-making enables some people with disability, especially people with cognitive disability, to understand risks of harm to themselves or others and to make decisions eliminating or mitigating the need to use restrictive practices.

We discuss supported decision-making further in Chapter 2, ‘Supported decision-making’, including a principle on access to support (see Recommendation 6.6). We also recommend a right to access supports for decision-making in Volume 4, *Realising the human rights of people with disability*.

The ALRC, in its *Equality, capacity and disability in Commonwealth laws* report, recommended the regulation of restrictive practices in the context of the NDIS should take account of its recommended National Supported Decision-Making Principles.⁶⁹³ The ALRC noted that ‘supported decision-making could ... help reduce and avoid the use of restrictive practices for persons with disability’.⁶⁹⁴ As such, the ALRC encouraged supported decision-making before restrictive practices are used.⁶⁹⁵

However, the ALRC went further, stating that the application of its National Supported Decision-Making Principles requires the will, preferences and rights of persons to direct decisions about any use of restrictive practices.⁶⁹⁶

The National Framework has a guiding principle called ‘Person-centred focus’, which provides for ‘maximum respect for a person’s autonomy’. This includes:

- i. recognising the presumption of capacity for decision making;
- ii. seeking a person’s consent and participation in decision making (with support if necessary) prior to making a substitute decision on their behalf; and
- iii. engaging the appropriate decision maker and seeking consent where appropriate, where a decision must be made on behalf of a person.⁶⁹⁷

As noted above, the Aged Care Royal Commission recommended that restrictive practices should only be used ‘with the documented informed consent of the person receiving care or someone authorised by law to give consent on that person’s behalf’.⁶⁹⁸

The exposure draft of the Persons with Disability (Regulation of Restrictive Practices) Bill 2021 in New South Wales proposes that for a restrictive practice to be authorised, consent from the NDIS participant or an ‘appropriate trusted person’ be required in most situations.⁶⁹⁹ However, as noted above, it is not clear if the Bill will be progressed.

We agree with the ALRC that supported decision-making should be promoted as a means of reducing and preventing the use of restrictive practices. This is reflected in our recommended Principle 1 (see Recommendation 6.6). However, we have concerns about including a requirement for people with disability to consent to the use of restrictive practices, particularly in the context of disability service provision.

First, this gives rise to complex human rights considerations around whether it is appropriate to require someone to consent to a practice that may cause them harm.

Second, until broader reforms to embed supported decision-making and address the systemic drivers of restrictive practices take effect, a consent requirement may lead to unintended consequences. In particular, until supported decision-making is introduced across legal frameworks and settings, a consent requirement may lead to an increase in substitute decision-making. Decisions may then be made on the basis of ‘best interests’ rather than a person’s ‘will and preferences’. It has been suggested that recent reforms in aged care, which require consent for the use of restrictive practices, may have led to an increase in applications for guardianship over people deemed to be unable to consent and without supporters or representative decision-makers in their lives.⁷⁰⁰

We consider that a better approach is for states and territories to establish a Senior Practitioner or equivalent authority to authorise and oversee the use of restrictive practices in disability service provision. Such an authority can be expressly charged with reducing and eliminating the use of restrictive practices, responding to evolving human rights considerations and legal and policy landscapes over time.

We discuss the role of senior practitioner later in this section.

Review of decisions to authorise restrictive practices

States and territories should require decisions authorising the use of restrictive practices to be subject to independent review.

As we discussed in Section 5.3, Victoria,⁷⁰¹ South Australia,⁷⁰² the Australian Capital Territory⁷⁰³ and Northern Territory⁷⁰⁴ provide for a right of review of a decision authorising the use of restrictive practices in the NDIS context by their respective tribunals. In Queensland, QCAT can review the approval of containment or seclusion⁷⁰⁵ and decisions made by a guardian about restrictive practices.⁷⁰⁶

In education and justice settings, few options are available for independent review of decisions to authorise restrictive practices. Only the Australian Capital Territory provides avenues for external, independent review of the use of restrictive practices in education and in youth detention, as discussed in Section 5.3.

In health and mental health settings, people have more avenues to seek recourse for decisions relating to restrictive practices. However, these avenues might involve making a complaint about the use of restrictive practices, rather than seeking review of a decision to authorise their use.

For example, in New South Wales, the Northern Territory, South Australia, Tasmania and Victoria, complaints about general health practitioners or organisations may be made to health care complaints commissions.⁷⁰⁷ The ACT Human Rights Commission handles complaints about the provision of health services in the Australian Capital Territory.⁷⁰⁸ In Queensland, the Office of the Health Ombudsman receives complaints about health services.⁷⁰⁹ In Western Australia, complaints about health or mental health services may be made to the Health and Disability Services Complaints Office.⁷¹⁰

Mental health review tribunals may review decisions about restrictive practices in mental health settings in some states and territories.⁷¹¹ In Victoria, the Mental Health Complaints Commissioner deals with complaints about public mental health services.⁷¹²

We recognise that decisions to use restrictive practices may need be made in emergency situations or otherwise as an immediate response, particularly in justice or health settings. Where restrictive practices are used in an emergency, they will often not be the subject of any prior authorisation. This means there will be no decision to authorise restrictive practices to be reviewed, though people should have avenues for making a complaint about their use.

People with disability may be subjected to restrictive practices that have been formally authorised through a behaviour support plan or otherwise, in numerous contexts. These include, for example, students with disability in education settings and people with disability receiving health or mental health care. In principle, people with disability subjected to a formal authorisation process for the use of restrictive practices should have the same right of review, regardless of where they live or the context in which the restrictive practices are to be used.

All decisions to authorise the use of restrictive practices on people with disability should be subject to independent review. Civil and administrative tribunals have experience and expertise in reviewing decisions to authorise the use of restrictive practices in a number of states and territories, as they play this role already in relation to disability service settings. For this reason, civil and administrative tribunals may be the appropriate bodies to review authorisation decisions in other contexts. Mental health review tribunals, where they exist, may be appropriate forums to review authorisation decisions in the context of mental health.

Independent oversight and monitoring

We also recommend that states and territories require that the use of restrictive practices should be subject to independent oversight and monitoring:

- In disability service settings, we recommend the Senior Practitioner or equivalent independent authority should be responsible for oversight and monitoring of the use of restrictive practices. This is discussed further below.
- In other settings, an agency should be responsible for the oversight and monitoring of the use of restrictive practices. Each state or territory will have to determine the appropriate agency for this purpose.
- In Volume 11, *Independent oversight and complaint mechanisms*, we discuss several mechanisms relevant to the oversight and monitoring of restrictive practices, including:
 - community visitor schemes
 - reportable conduct schemes
 - National Preventive Mechanisms under the *Optional Protocol to the Convention Against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment*.

Reducing and eliminating restrictive practices through a senior practitioner model

We recommend that states and territories introduce or clarify the role of a senior practitioner or equivalent independent authority.

As noted in Section 5.3, a number of states and territories have a Senior Practitioner or Senior Authorising Officer responsible for authorising the use of restrictive practices in disability service settings.

In addition to this function, Senior Practitioners in the Australian Capital Territory, Victoria and the Northern Territory have broad functions around promoting the reduction and elimination of the use of restrictive practices or protecting the rights of people subjected to restrictive practices.⁷¹³ Senior Practitioners in these jurisdictions also have a role in:

- monitoring or overseeing the use of restrictive practices⁷¹⁴
- developing guidelines and standards on restrictive practice use for disability service providers⁷¹⁵
- providing information and advice to people with disability and disability service providers about restrictive practices.⁷¹⁶

The Senior Practitioner in the Australian Capital Territory has complaint handling and investigation powers,⁷¹⁷ while the Victorian Senior Practitioner is empowered to investigate, audit and monitor the use of restrictive practices.⁷¹⁸ The Tasmanian and Victorian Senior Practitioners' functions also include collating and publishing data relating to the use of restrictive practices.⁷¹⁹

There are currently proposals for a senior practitioner model in Queensland⁷²⁰ and Western Australia.⁷²¹

In its report on the Victorian education system regarding the experience of students with disability, the Victorian Equal Opportunity and Human Rights Commission said:

The role of the Senior Practitioner to monitor the use of restrictive interventions in disability services has made a measurable contribution to the reduction in the use of seclusion and restraint in disability services. This has delivered significant improvements for the human rights and dignity of people with disabilities and potentially may also lead to cost savings for disability services over time.⁷²²

In line with Victoria, the Northern Territory and the Australian Capital Territory, we consider that the Senior Practitioner (or equivalent) should be responsible for protecting the rights of people with disability subjected to restrictive practices in each jurisdiction.⁷²³ The Senior Practitioner should be the primary agent responsible for each jurisdiction's efforts to reduce and eliminate the use of restrictive practices in disability service settings. The Senior Practitioner should pursue these outcomes through raising awareness about restrictive practices and behaviour

support planning among people with disability, their families, friends and supporters, disability service providers and the broader community.

The role should also support disability service providers by developing guidelines and standards and providing expert advice on the use of restrictive practices and behaviour support planning. The NDIS Commission does provide guidance to NDIS service providers and behaviour support practitioners on the appropriate use of restrictive practices.⁷²⁴ However, each state and territory Senior Practitioner could adapt their guidance to the particular characteristics of the jurisdiction, considering its regulatory framework, demographic make-up and the issues requiring attention most urgently. The educational, development and capacity building functions described here reflect those of Senior Practitioners in Victoria, the Australian Capital Territory, the Northern Territory and Tasmania.⁷²⁵

The Senior Practitioner should be responsible for authorising the use of restrictive practices in disability settings, in accordance with procedures consistent with the Draft Principles for Consistent Authorisation (see Section 5.2).

Finally, the complaint-handling and investigatory powers of the Senior Practitioner or equivalent authority should mirror those in the Australian Capital Territory and allow them to:

- receive complaints about the use of restrictive practices and the quality of behaviour support planning
- investigate the use of restrictive practices and the quality of behaviour support planning, either in response to complaints or at its own motion
- to act in response to complaints and investigations if satisfied, on reasonable grounds, of the necessity of doing so.

The Senior Practitioner should be an independent statutory authority. Any person appointed to the role of Senior Practitioner should have the appropriate clinical qualifications and experience to perform the functions and exercise the powers of the role.

After an initial period of implementation and evaluation, states and territories should consider extending the role of the Senior Practitioner to the authorisation of restrictive practices in other settings such as health, education, justice and out of home care.

Recommendation 6.35 Legal frameworks for the authorisation, review and oversight of restrictive practices

- a. States and territories should ensure appropriate legal frameworks are in place in disability, health, education and justice settings, which provide that a person with disability should not be subjected to restrictive practices, except in accordance with procedures for authorisation, review and oversight established by law.

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- b. The legal frameworks should incorporate the following requirements, appropriately adapted to sector-specific contexts.
- Restrictive practices should only be used:
 - as a last resort, in response to a serious risk of harm to a person with disability or others, and only after other strategies, including supported decision-making, have been explored and applied
 - as the least restrictive response possible to ensure the safety of the person with disability or others
 - to the extent necessary to reduce the risk of harm and proportionate to the potential negative consequences from the use of restrictive practices
 - for the shortest time possible.
 - Decisions to authorise restrictive practices should be subject to independent review.
 - The use of restrictive practices should be subject to independent oversight and monitoring.
- c. The legal frameworks should set out the powers and functions of a Senior Practitioner for restrictive practices in disability service provision (or equivalent authority). These powers and functions should include:
- promoting the reduction and elimination of the use of restrictive practices
 - protecting and promoting the rights of people with disability subjected to restrictive practices
 - developing and providing information, education and advice on restrictive practices to people with disability, their families and supporters, and the broader community
 - considering applications to use restrictive practices in disability service settings and authorising their use according to procedures consistent with the Draft Principles for Consistent Authorisation
 - developing guidelines and standards, and providing expert advice, on restrictive practices and behaviour support planning
 - receiving complaints about the use of restrictive practices and the quality of behaviour support planning
 - investigating the use of restrictive practices and the quality of behaviour support planning, either in response to complaints or of its own motion
 - acting in response to complaints and investigations where appropriate.

Prohibiting the use of certain restrictive practices

We recognise it may not be possible to have an entirely consistent set of prohibitions across all settings equally given the very different contexts in which restrictive practices are used. However, as a general principle, prohibitions should apply as consistently as possible so that people with disability have similar levels of protection no matter where they live. Prohibitions on restrictive practices should therefore be consistent within each setting, in disability, health and mental health, or education environments, across all states and territories.

We consider that state and territory governments should take immediate action to prevent the use of certain restrictive practices in disability, health and education settings.

We recommend seclusion of children be prohibited in disability, education, health and mental health settings. This aligns with existing approaches in a number of states and territories:⁷²⁶

- New South Wales, Victoria, Queensland and South Australia already prohibit seclusion in the context of education to various degrees
- seclusion of children and young people is prohibited in disability settings in New South Wales and the Northern Territory.

We also recommend all states and territories immediately adopt, in full, the Disability Reform Council's agreed list of prohibited practices, for disability service settings.⁷²⁷

We recommend the strongest prohibitions that currently apply in Australian jurisdictions be consistently adopted in health and education settings across all states and territories. To effect change immediately, existing policy frameworks may need to be amended to provide that these restrictive practices are not permissible. We acknowledge this is not strictly a legal prohibition. However, once appropriate legal frameworks are established in line with Recommendation 6.35, prohibitions should be incorporated in legislation.

We recommend state and territory governments should provide the following are not permitted in health and mental health settings:

- using seclusion and restraint as a means to reduce behaviours not associated with immediate risk of harm⁷²⁸
- using seclusion and restraint as a form of discipline, punishment or threat⁷²⁹
- restrictive practices that involve or include deliberate infliction of pain to secure compliance⁷³⁰
- using prone or supine holds, using any restraint intended to restrict or affect respiratory or digestive function, or forcing a person's head down to their chest⁷³¹
- secluding a person who is also mechanically restrained⁷³²
- secluding a person who is actively self-harming or suicidal⁷³³

-
- using metal handcuffs or hard manacles as a form of mechanical restraint (unless under police or other custodial supervision while in the health facility)⁷³⁴
 - vest restraints for older people⁷³⁵
 - neck holds⁷³⁶
 - drugs or higher doses of drugs, that create continuous sedation to manage behaviour.⁷³⁷

We recommend state and territory governments should provide the following are not permitted in education settings:

- the use of restrictive practices:⁷³⁸
 - as a form of discipline, punishment or threat
 - as a means of coercion or retaliation
 - in response to property destruction
 - for reasons of convenience
- life threatening physical restraints, including physical restraints that restrict a student's breathing or harm the student by:⁷³⁹
 - covering the student's mouth or nose, or in any way restricting breathing
 - taking the student to the ground into the prone or supine position
 - causing hyperextension or hyperflexion of joints
 - applying pressure to the neck, back, chest or joints
 - deliberately applying pain to gain compliance
 - causing the student to fall
 - having a person sit or kneel on the student
- chemical restraints⁷⁴⁰
- mechanical restraints⁷⁴¹
- 'clinical' holding, which is holding 'in order to provide essential healthcare or personal care':⁷⁴²
 - as a behaviour support strategy
 - to enforce the compliance of a student in undertaking personal care that is non-urgent and does not present a risk to the student
 - to punish a student
- denial of key needs, such as food and water.⁷⁴³

Recommendation 6.36 does not include prohibitions in justice settings. However, in Volume 8, we discuss and make a recommendation about solitary confinement and seclusion of children and young people in youth detention.

Recommendation 6.36 Immediate action to provide that certain restrictive practices must not be used

State and territory governments should immediately:

- Adopt the list of prohibited forms of restrictive practices agreed by the former Disability Reform Council in 2019 and provide that the use of seclusion on children and young people is not permitted in disability service settings.
- Provide that the following are not permitted in health and mental health settings:
 - using seclusion and restraint as a means to reduce behaviours not associated with immediate risk of harm
 - using seclusion and restraint as a form of discipline, punishment or threat
 - restrictive practices that involve or include deliberate infliction of pain to secure compliance
 - using prone or supine holds, using any restraint intended to restrict or affect respiratory or digestive function, or forcing a person's head down to their chest
 - secluding a person who is also mechanically restrained
 - secluding a person who is actively self-harming or suicidal
 - using metal handcuffs or hard manacles as a form of mechanical restraint (unless under police or other custodial supervision while in the health facility)
 - vest restraints for older people
 - neck holds
 - drugs, or higher doses of drugs, that create continuous sedation to manage behaviour
 - seclusion of children and young people.
- Provide that the following are not permitted in education settings:
 - the use of restrictive practices:
 - as a form of discipline, punishment or threat
 - as a means of coercion or retaliation

- in response to property destruction
- for reasons of convenience
- life threatening physical restraints, including physical restraints that restrict a student's breathing or harm the student by:
 - covering the student's mouth or nose, or in any way restricting breathing
 - taking the student to the ground into the prone or supine position
 - causing hyperextension or hyperflexion of joints
 - applying pressure to the neck, back, chest or joints
 - deliberately applying pain to gain compliance
 - causing the student to fall
 - having a person sit or kneel on the student
- chemical restraints
- mechanical restraints
- clinical holding:
 - as a behaviour support strategy
 - to enforce the compliance of a student in undertaking personal care that is non-urgent and does not present a risk to the student
 - to punish a student
- denial of key needs, such as food and water.

5.6. Psychotropic medication

Overuse and over prescription

... if they are prescribed medicines that don't have evidence for benefit, and they are solely being prescribed because of their tranquilising effects or their sedative effects, rather than addressing the underlying problems ... then that is abuse. And it's neglecting to give them the proper care that they are entitled to as human beings.⁷⁴⁴

People with cognitive disability

Psychotropic medication is any drug capable of affecting the mind, emotions or behaviour. This category of medication includes anti-psychotics, anti-depressants, and mood stabilisers.⁷⁴⁵ We acknowledge that, when prescribed appropriately, psychotropic medication can improve health outcomes, especially for patients with mental health conditions. However, evidence at Public hearing 6 demonstrated that it can be difficult to determine whether psychotropic medications have been prescribed to treat mental health conditions or as a chemical restraint to control behaviour.

Several witnesses at Public hearing 6 expressed concern about the extent of use and potential misuse of psychotropic medication as a form of chemical restraint in response to 'behaviours of concern'. Witnesses shared their experiences of people with cognitive disability being prescribed or administered:

- antipsychotic medications in dosage level so significant that they considered it constituted a form of abuse⁷⁴⁶
- a 'large cocktail' of sedative, psychotropic and antidepressant medications without any additional forms of behaviour support.⁷⁴⁷

Documents in evidence indicate psychotropic medication is extensively prescribed and administered to people with cognitive disability in both Australia and other developed countries.⁷⁴⁸ This conclusion is supported by data the NDIS Commission provided, which confirms chemical restraints can be administered to an NDIS participant three or more times a day.⁷⁴⁹

The Commissioners' *Report of Public hearing 6* found that psychotropic medication is over-prescribed to people with cognitive disability.⁷⁵⁰ In particular, it is over-prescribed and over-used as a response to 'behaviours of concern' people with cognitive disability may display.⁷⁵¹

Past reports and reviews concluded psychotropic medications are often administered to people with disability who do not have a mental health condition. In 2016, the Queensland Office of the Public Advocate expressed 'significant concern' about the outcome of its review of deaths in care of people with disability related to the use of psychotropic medication.⁷⁵² The review showed that 49 per cent of people with disability were administered psychotropic medication in cases where, based on available information, few seemed to have been diagnosed with mental illness.⁷⁵³

We heard similar conclusions have been made in reviews of deaths of people with intellectual disability in residential care in New South Wales.⁷⁵⁴

Effectiveness of psychotropic medication and side effects

The Commissioners' *Report of Public hearing 6* found:⁷⁵⁵

- people with cognitive disability tend to experience more side effects, including atypical effects, of psychotropic medication than people without disability
- the adverse effects of psychotropic medication can lead to people with cognitive disability displaying increased and varied 'behaviours of concern'
- the adverse effects of psychotropic medication are compounded for many people with cognitive disability, given the prevalence of polypharmacy (that is, the use of multiple medications at once) among that population.

The report also found that:⁷⁵⁶

- In the short term, in some circumstances the sedative effects of psychotropic medication may reduce behaviours of concern displayed by people with cognitive disability.
- The evidence does not suggest that psychotropic medication alone is an effective response, except sometimes in the short term, to behaviours of concern displayed by people with cognitive disability. Psychotropic medication is unlikely to address the underlying causes of the behaviours of concern.

At Public hearing 6, Dr Jane Law, consultant general practitioner at the NSW Developmental Disability Health Unit, shared her experience of two patients who had self-harmed, but psychotropic medication had not altered their pattern of behaviour.⁷⁵⁷ Further investigations determined both patients were blind due to cataracts. Cataract extraction and lens replacement reduced the patients' levels of self-harm.⁷⁵⁸

Regulatory protection against use of psychotropic medication

We consider that regulation of the prescription of psychotropic medication is failing to adequately protect people with disability. Public hearing 6 examined regulation of psychotropic medication in Queensland. The Commissioners' report found that the distinction in Commonwealth and Queensland legislation between psychotropic medication prescribed for treatment of people with cognitive disability and its use as a chemical restraint is problematic in practice.⁷⁵⁹ One reason for this is that medical practitioners are not bound by the rules governing the use of psychotropic medication as a chemical restraint, making it difficult to control inappropriate prescribing of psychotropic drugs.⁷⁶⁰ Prescribing medical practitioners across Australia are not bound by the *NDIS Restrictive Practices Rules*.

The distinction between using psychotropic drugs as a treatment for a diagnosed mental health condition and using them as a chemical restraint to address behaviours of concern is much less clear-cut than the regulatory regimes seem to assume. Also, medical practitioners with authority to prescribe psychotropic drugs do not always accept the distinction or interpret the regulatory requirements to permit psychotropic drugs to be prescribed as chemical restraints more freely than is desirable.

The distinction drawn by legislation and regulations appears on its face to be reasonable. However, it raises questions about:

- how medical practitioners or other decision-makers determine in a particular case if psychotropic medication is being used as a treatment or as a restraint
- whether the criteria on which the determination is made should be specified in legislation or other authoritative instruments
- whether all medical practitioners have sufficient expertise to properly diagnose and treat mental health conditions in people with cognitive disability
- the extent to which medication is prescribed and administered under the guise of treatment, when it is in fact being used as a restraint.

Attitude of medical professionals to the concept of chemical restraint

The Commissioners' *Report of Public hearing 6* found many medical practitioners do not have the training or experience to distinguish between using psychotropic medication to treat mental health conditions and using them as chemical restraints to address 'behaviours of concern'. Some medical practitioners reject the distinction.⁷⁶¹

Evidence at Public hearing 6 suggested decision-makers who represent or have authority to act for people with disability, encountered resistance when they asked medical practitioners about prescribing psychotropic medications. Dr Niki Edwards, a researcher and lecturer in the School of Public Health and Social Work at Queensland University of Technology, said 'many prescribers were hostile towards guardians questioning their decisions in regard to the prescription of psychotropic medication to adults with intellectual disability'.⁷⁶² A study led by Dr Edwards found some medical practitioners were defensive and appeared to interpret questions by guardians as a professional 'affront'. Some guardians felt concern the treating doctor would stop seeing the patient if questions were asked.⁷⁶³ Also, the study demonstrated the language of 'chemical restraint' evoked strong negative responses among many stakeholders, including health professionals.⁷⁶⁴

Contribution of diagnostic overshadowing to misuse of medication

In Public hearings 4 and 6, the Royal Commission heard evidence of 'diagnostic overshadowing'. This occurs when a health professional attributes symptoms or behaviours to a person's disability rather than to health conditions unrelated to the disability.⁷⁶⁵ It can also occur when a particular condition is undertreated or not diagnosed because the focus is on other health issues. Diagnostic overshadowing can result in delayed diagnosis or misdiagnosis of serious medical issues.⁷⁶⁶

In Public hearings 4 and 6 we received evidence of the link between diagnostic overshadowing and the misuse or overuse of psychotropic medication:

- In adult health care, patients displayed ‘behaviours of concern’ including ‘extreme levels of self-harm’ and were prescribed psychotropic medication.⁷⁶⁷ But the patients had underlying health issues requiring treatment – it was found they had gastro-oesophageal reflux disease, constipation or osteoarthritis, all of which contribute to pain. Once appropriate treatment for these health issues was administered, the ‘behaviours of concern’ were resolved or much reduced.⁷⁶⁸
- In disability accommodation, disability workers sometimes misattributed certain behaviours to a person’s disability rather than questioning whether they might indicate medical problems or conditions.⁷⁶⁹ Support workers often have little support or advice available when ‘behaviours of concern’ arise. This leads them to resort to medication to resolve the situation.⁷⁷⁰

We discuss diagnostic overshadowing further in Chapter 4.

Tash*

**‘Chemical restraint and seclusion are absolute punishments.
They are not therapies to help calm patients.’**

In the early 2000s Tash was ‘extremely depressed’ and tried to take her own life. She was admitted to a hospital psychiatric unit under a treatment order.

‘This was my first real stay in a psych ward and I was very frightened,’ she told the Royal Commission.

Tash was in her late 30s.

At the end of her first week, she experienced a thyroid storm which was misdiagnosed.

Instead of receiving treatment, the psychiatric registrar placed Tash in seclusion.

‘I was slapped in the face by a wardsman, who then kicked my legs out from under me ... then forcibly carried me to a seclusion room and held me face down.’

Tash said he pushed his knee into her back and she was ‘gasping for air’.

‘The registrar then injected me in the shoulder with a chemical that totally immobilised me such that I couldn’t move or speak.’

The staff then left the room and locked the door.

‘I cannot describe the level of panic I felt.’

After about half an hour the registrar checked on Tash and suspected ‘some deeper trauma’.

Blood tests revealed Tash needed an emergency thyroid ablation.

When Tash was discharged she complained to the hospital about her treatment but the doctor defended her actions.

The doctor said the thyroid problem wasn’t diagnosed before it became an emergency because there was a delay in receiving Tash’s blood test results.

The restraint and seclusion had been used as a last resort and while the doctor regretted Tash saw it in a negative light, 'it had all "worked out well" in the end'.

But it didn't work out well for Tash.

Tash said the treatment 'deeply added to the trauma I was already suffering'.

When Tash was in her late teens she had been repeatedly locked in a small room, beaten, restrained and then left alone.

'Many horrible and disgusting things were ... done to me.'

This included being 'threatened with electrocution and murder if I spoke to authorities, at one time being strapped down and wired up with electrodes to intimate parts of my body'.

After about four months the police became involved.

Tash said she was shocked by the parallels between these two incidents.

Both included 'slapping, tackling, being held face down, restricted breathing, absolute restraint, and being locked into a small room not knowing what was going on or what was going to happen to me'.

Tash no longer trusts psychiatrists and said she needed counselling 'to get over what the psychiatric system did to me'.

Tash's believes seclusion and chemical restraint never benefit patients and are only used to make patients 'shut up and shut down in under-resourced and unpleasant working environments'.

She would like these 'treatments' to be banned. If they are used, 'then the psychiatrist or registrar must be held to account' and each incident must be investigated by independent authorities.

* This is a de-identified narrative of an experience shared with us in a submission or private session. The person who shared their experience was not a witness. They did not give evidence, take an oath or give an affirmation. Nothing in this narrative represents a finding of the Royal Commission and any views expressed are those of the person, not of the Royal Commission.

Reducing the inappropriate use of psychotropic medication

... people [should be] able to access treatment that is not abusive or violent; treatment that meets their needs, upholds their rights and provides compassionate care to enable people to live their best lives⁷⁷¹

Education and training in the health and disability sectors

In their *Report of Public hearing 6*, Commissioners found that the over-use and misuse of psychotropic medication against people with cognitive disability who display behaviours of concern is a problem that concerns both the health and disability sectors and therefore requires multidisciplinary collaboration to address it.⁷⁷²

The Report concluded that health and allied professionals need better training and skills to:⁷⁷³

- address attitudes, assumptions or beliefs that behaviours of concern are the fault of the person with cognitive disability, or are the product of an unalterable inherent condition
- recognise and address the underlying causes of behaviours of concern, rather than focusing on the behaviours themselves
- enhance methods of communication to ensure that informed consent to the use of psychotropic medication is given wherever possible
- recognise and implement positive behaviour support as an alternative to psychotropic medication.

The Report identified a clear need for widely accessible information and guidance for the health and disability sectors on:⁷⁷⁴

- managing behaviours of concern with both medication and positive behaviour support
- the efficacy of psychotropic medication in reducing behaviours of concern
- the prevalence and severity of side effects of this medication for people with cognitive disability
- the process for the safe de-prescription of psychotropic medication where it is used to manage behaviours of concern.

The Commissioners' *Report of Public hearing 10* includes a recommendation addressing the need for health professionals to build capabilities 'in understanding, preventing and managing 'behaviours of concern', particularly through means other than restrictive practices'.⁷⁷⁵ In

Chapter 4, we support full implementation of the recommendations in the Commissioners' *Report of Public hearing 10*.

A recent pilot study explored the use of targeted training for Australian disability support workers about psychotropic medications based on the Short-Term Psycho-Education for Caregivers to Reduce Overmedication of People with Intellectual Disabilities (SPECTROM) program developed in the United Kingdom. This study found the training increased staff knowledge and was useful and valid. However, since it was a pilot study involving a small number of participants, the researchers said that further refinement and evaluation of the impact of the training on outcomes for people with intellectual disability is required.⁷⁷⁶

Dr Jeffery Chan, the NDIS Commission's Senior Practitioner, informed us the Australian Government National Roadmap for Improving the Health of People with Intellectual Disability (National Roadmap), released in August 2021, includes measures to develop:⁷⁷⁷

- best practice quality standards for prescribing psychotropic medication
- resources and pathways to connect health and disability services
- resources and training to improve disability support providers' health literacy
- intellectual disability competencies, curricula content, and tools and resources to develop health professionals' knowledge of intellectual disability and instil positive attitudes toward people with disability.

Joint statement on the inappropriate use of psychotropic medicines to manage the behaviours of people with disability and older people

In March 2022, the NDIS Commissioner, the CEO of the ACSQHC and the Commissioner of the Aged Care Quality and Safety Commission (ACQSC) released a Joint statement on the inappropriate use of psychotropic medicines to manage the behaviours of people with disability and older people (Joint statement).⁷⁷⁸ The Joint statement acknowledged that psychotropic medicines are being overprescribed and overused – in particular for older people and people with disability.⁷⁷⁹

The NDIS Commission, ACSQHC and the ACQSC have committed to work together to reduce the inappropriate use of psychotropic medicines by:⁷⁸⁰

- raising awareness of the risks associated with inappropriate use of psychotropic medicines among healthcare, aged care and disability workforces
- supporting improvements to the availability and quality of behaviour support planning, and preventative and de-escalation strategies
- strengthening understanding and capacity for appropriate informed consent, prescribing, dispensing, administration and cessation of psychotropic medicines.

In the health sector, the ACSQHC is developing the Psychotropic Medicines in Managing

Changed Behaviours Clinical Care Standard (the Psychotropic Medicines Standard).⁷⁸¹

While clinical care standards the ACSQHC develop are not mandatory, the National Safety and Quality Health Service Standards strongly support the use of clinical care standards, and they are implemented in many acute health services.⁷⁸² The Psychotropic Medicines Standard will provide a series of quality statements describing best practice care. It should assist clinicians and health services reflect on whether psychotropic medicines should be prescribed and, if they are, why they are being prescribed.⁷⁸³ The Psychotropic Medicines Standard is expected to recommend managing behaviours without using psychotropic medicines, including by using environmental, psychosocial, behavioural and other non-drug methods.⁷⁸⁴

Public consultation on the draft Psychotropic Medicines Standard and related resources closed on 8 May 2023. The ACSQHC intends to launch the Psychotropic Medicines Standard in early 2024.⁷⁸⁵ The NDIS Commission will consider the quality statements in the Psychotropic Medicines Standard and ensure they are appropriately reflected in its information and resources for specialist behaviour support providers, NDIS behaviour support practitioners, implementing providers, NDIS participants and their families and other supporters.⁷⁸⁶

For the disability sector, the NDIS Commission has published:

- a detailed Regulated Restrictive Practices Guide,⁷⁸⁷ which outlines a number of important considerations when using chemical restraints (among other forms of restraints)⁷⁸⁸
- a Medication Purpose Form⁷⁸⁹ to enable NDIS providers, participants and carers to ask a prescribing practitioner to identify the medication purpose and side effects⁷⁹⁰
- practice alerts for NDIS providers on psychotropic medication – for example, on the need for regular, comprehensive health assessments⁷⁹¹
- expanded evidence summaries for behaviour support practitioners and registered NDIS providers that implement behaviour support plans.⁷⁹²

Dr Chan also advised that the NDIS Commission is:

- tailoring resources from the SPECTROM training for the Australian disability workforce. The revised resources will increase disability support workers' knowledge about psychotropics and their alternatives⁷⁹³
- close to finalising a project to identify existing communication resources to help reduce or eliminate the inappropriate use of psychotropic medicines in older people and people with disability⁷⁹⁴
- intending to consult with experts to understand how to improve or expand resources for NDIS behaviour support practitioners on psychotropic medicines⁷⁹⁵
- intending to consult NDIS participants to identify what information and resources they need on psychotropic medications and seek feedback on information and resources published to date.⁷⁹⁶

Data linkage study on the use of psychotropic medicines

In August 2022, the NDIS Commission's Behaviour Support team commenced the data linkage study, Psychotropic use in people with disability in Australia.⁷⁹⁷ The study aims to answer the following questions:⁷⁹⁸

- What are the rates of prescribing psychotropic drugs and use in Australians with disability? How does this compare across different types of disability and the general population? How has this changed over time?
- To what extent is the prescribing of psychotropic drugs for people with disability associated with a diagnosed mental disorder?
- Are people with disability receiving psychotropics: referred to MBS-subsidised mental health services? Do they undergo medication management reviews; receive comprehensive health assessments; and have healthcare management plans in place?
- What are the rates of psychotropic-related adverse effects in people with disability? Are those people who experience adverse effects referred to appropriate services?

The NDIS Commission hoped to publish findings on the first two research questions in mid-2023, the third by the end of 2023, and the fourth in 2024, subject to available resources.⁷⁹⁹ The data linkage study is an important first step to address current information gaps identified in Public hearing 6, but should not be a one-off exercise. This data should be collected and published on a regular basis to promote transparency, identify trends and inform strategies to reduce the inappropriate prescription of psychotropic medication for people with disability, particularly cognitive disability.

Medication reviews and annual health assessments

Several witnesses suggested in Public hearing 6 that regular medication reviews and comprehensive health care checks should be required to address concerns about the misuse and continued use of psychotropic medication in response to behaviours of concern and as a form of chemical restraint.⁸⁰⁰ Medication reviews are useful in monitoring for adverse side effects and providing an opportunity to initiate deprescribing of psychotropic medications.⁸⁰¹ The Pharmaceutical Society of Australia has continued its advocacy in this area, releasing a report in July 2022 that recommends the increased use of and access to comprehensive medication management review services for people with disability.⁸⁰²

In Chapter 4, we note the priority being given to improving annual health assessments for people with intellectual disability under the National Roadmap. Dr Chan has also provided information describing the role of the National Roadmap in improving opportunities for reviewing medications. He stated:

measures to better promote the use of annual health assessments and other relevant MBS items to people with intellectual disability, their families, carers and support workers, and supporting GPs, practice nurses, and people with intellectual disability

and their supports to access and use the Comprehensive Health Assessment Program tool, should improve opportunities for reviewing medications, including psychotropic medicines, their side effects, and whether they are appropriate for the person with intellectual disability.⁸⁰³

Reporting and evaluation of key measures under the Joint statement

The work being undertaken under the Joint statement by the NDIS Commission, the ACSQHC and the ACQSC, combined with commitments under the National Roadmap, address key issues identified in Public hearing 6 about the over-use of psychotropic medication for people with cognitive disability.

Developments following the Joint statement are positive. However, there have been no firm commitments to publish regular progress reports or evaluate their impact to determine whether they reduce the inappropriate use of psychotropic medication against people with disability. There should be ongoing monitoring, independent evaluation and public reporting on the collective efforts of the three commissions under the Joint statement to confirm these are resulting in practical changes.

Ongoing data collection and reporting on the use of psychotropic medication against people with disability, particularly cognitive disability, is also essential. It will provide transparency and accountability and ensure that the actions result in real improvements to the lives of people with disability. Data collection and reporting on the use of psychotropic medication against people with disability, particularly cognitive disability, should be broadened to settings beyond the NDIS over time.

Recommendation 6.37 Data collection and public reporting on psychotropic medication

The NDIS Quality and Safeguards Commission, the Australian Commission on Safety and Quality in Health Care and the Aged Care Quality and Safety Commission should:

- publish joint annual progress reports on implementation of measures under the Joint statement on the inappropriate use of psychotropic medicines to manage the behaviours of people with disability and older people
- commission an independent evaluation of these measures to determine whether they have resulted in a reduction in the use of psychotropic medicines against people with cognitive disability. The evaluation should be co-designed with people with cognitive disability and their representative organisations and its results should be publicly reported.

5.7. Restrictive practices research

Lack of empirical research on restrictive practices

We commissioned two research reports on restrictive practices:

- *Restrictive practices: A pathway to elimination* from the University of Melbourne, University of Technology Sydney and University of Sydney (*Pathway to elimination* report)
- *Reducing restrictive practices: a review of evidence-based alternatives* from the University of New South Wales (*Reducing restrictive practices* report).

The *Pathway to elimination* report found there has been little scholarly research into the experiences of people with disability subjected to restrictive practices in Australia.⁸⁰⁴ It recognised:

there has ... been little to no research into the specific experiences of restrictive practices for LGBTQIA+ people with disability, or culturally and linguistically diverse people with disability. Only a few studies consider the experiences of First Nations people with disability.⁸⁰⁵

The *Reducing restrictive practices* report reported similar gaps in research.⁸⁰⁶

The experience of First Nations people with disability subjected to restrictive practices is particularly important in the broader context of ongoing colonisation, systemic racism and over-representation in institutional settings. There is a lack of quantitative data and academic research on the experiences of First Nations people with disability, but those experiences were examined during our public hearings. For example, at Public hearing 27, we heard evidence about children with disability being subjected to solitary confinement in the Banksia Hill Detention Centre (Banksia Hill) in Western Australia.⁸⁰⁷ The evidence we received suggested on an average day in Banksia Hill more than 70 per cent of the detainees are First Nations children.⁸⁰⁸

Other evidence given at Public hearing 27 included:

- A First Nations person with disability being subjected to chemical restraints from a young age, experiencing difficulty in accessing supports and not having a high-quality behaviour support plan in place.⁸⁰⁹
- First Nations prisoners returning from 'sorry business' who were subjected to solitary confinement. In one case, this resulted in a prisoner being confined for 63 days.⁸¹⁰
- First Nations people with cognitive disability in forensic health and correctional facilities being subjected to the sustained use of chemical restraint and prolonged seclusion, in conditions described as 'filthy and degrading'⁸¹¹ and amounting to 'cruel, inhuman or degrading treatment contrary to Australia's human rights obligations'.⁸¹²

This is consistent with the Northern Territory Office of the Public Guardian's response to the *Experience of First Nations people with disability in Australia issues paper*, which stated that First Nations people with disability in the criminal justice system are at:

greater risk of being subject to restrictive practices or abuse by other prisoners in response to behaviour that is attributable to their unmet need and removal from country, culture and support networks.⁸¹³

We discuss the experiences of First Nations people in detail in Volume 9, *First Nations people with disability*.

Limitations in the evidence base

Although more research in the use and regulation of restrictive practices is now taking place, it tends to concentrate on specific settings, cohorts of people and types of restrictive practices.⁸¹⁴

The *Pathway to elimination* report noted 'limitations within contemporary scholarship' on restrictive practices and said that further research is required'.⁸¹⁵ Likewise, the Victorian Government's submission to the Royal Commission called for systemic research on behaviour support and restrictive practices to support the reduction and elimination of restrictive practices.⁸¹⁶ We accept that further research is needed on 'what works' to reduce and eliminate restrictive practices.

Further research on the effectiveness of positive behaviour support practices

In preparing the *Pathway to elimination* report, the researchers considered whether positive behaviour support is effective in reducing and eliminating the use of restrictive practices. If so, they were asked to consider whether it is more effective for certain types of disability, restrictive practices, or settings.⁸¹⁷

Based on a review of the national and international scholarly literature, the *Pathway to elimination* report found that the evidence base for positive behaviour support is limited. Further, studies considered in the *Pathway to elimination* report often provide mixed or inconclusive results.⁸¹⁸ The report said the two core limitations of the existing evidence base are small sample sizes (some studies are based on a single case study design), and 'a lack of strength, accuracy and integrity' of research findings.⁸¹⁹

Several studies have reported positive outcomes from implementing positive behaviour supports. However, design limitations make it unclear whether and to what extent positive outcomes resulted from the positive behaviour supports.⁸²⁰ The *Pathway to elimination* report concluded that positive outcomes appear to occur for people with disability when:⁸²¹

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- staff are nonconfrontational and consistent in their communication with the person with disability
 - staff do not impinge on the autonomy of the person with disability
 - people with disability are enabled to participate in meaningful activities of their own choosing
 - the wishes of the person with disability are listened to and acted upon.

The researchers noted that these findings are ‘consistent with the understanding that perceived “behaviours of concern” are distress, protest and resistance made in a context of maladaptive “environments of concern”’.⁸²²

Overall, the researchers concluded:

it is not possible from the research literature currently available to generalise if positive behaviour support is more or less effective in certain settings. Nor is it possible from current research to determine if positive behaviour support is more or less effective when used in relation to certain types of disabilities, or used in the context of certain restrictive practices.⁸²³

The *Reducing restrictive practices* report reached a similar conclusion on strategies to prevent challenging behaviour, reduce the need to use restrictive practices or adopt alternative approaches where challenging behaviour occurs. It found ‘there are a number of evidence gaps; and no clear consensus as to what constitutes good practice or how to achieve change’.⁸²⁴

International approaches to reduce restrictive practices

The *Pathway to elimination* report recorded international approaches to reducing restrictive practices which have had varying success in mental health settings. However, the approaches are limited in their application to the settings in which restrictive practices are used towards people with disability. The researchers were unable to identify national or international approaches to the reduction and elimination of restrictive practice developed for, and evaluated in, disability service settings.⁸²⁵

The Safewards Model – England

The Safewards Model is a clinical model for the management of conflict in mental health settings. It was originally developed as a tool to create a safer environment for both staff and patients. The Safewards Model considers restrictive practices use, but it has a broader focus on understanding conflict, its causes and staff responses. Under the model, conflict arises within six ‘originating domains’: patient, community, patient characteristics, regulatory framework, staff team and physical environment. These domains can give rise to specific ‘flashpoints’ which can trigger a conflict incident. The model provides a range of evidence-based interventions that can be used to address various ‘flashpoints’ and reduce or eliminate the factors contributing to conflict.⁸²⁶

The Safewards Model had shown some positive effects in general mental health settings.⁸²⁷ However, a 2022 systematic review of the effectiveness of the Safewards Model concluded that while it has reduced conflict and containment in general mental health inpatient services, it is unclear if this extends to other settings.⁸²⁸

The Safewards Model has been trialled in Queensland, New South Wales and Victoria. Evaluations have provided mixed results:⁸²⁹

- In Queensland, ‘a study was undertaken into nursing perceptions of the factors impacting the implementation of the Safewards Model at three acute inpatient wards ... [which] concluded that staff engagement was a major factor for success, with some nurses expressing resistance to change’.
- In New South Wales, a study (which was not controlled or randomised) of the implementation of the model in one large metropolitan local health district in Sydney found it resulted in ‘a 23 per cent reduction in overall conflict and a 12 per cent reduction in containment’.
- In Victoria, a trial of the model was evaluated for its impacts on the use of seclusion. The evaluation found the model ‘was not robustly associated’ with reducing seclusion during the trial period. However, it noted there were ‘indications of a seclusion reduction trend’ one year after the trial period.
- The Victorian trial occurred across 18 public acute mental health inpatient units in 2017–18, and was followed by implementation in all inpatient units including adult, aged, youth and secure extended care units. The model is also being trialled in two emergency departments.⁸³⁰

The No Force First Project – England

In 2013, a large National Health Service trust in North West England designed and implemented the No Force First Project (No Force First) for people using mental health and learning disability inpatient services.⁸³¹ The project is based on the ‘proposition that effective recovery for people receiving services required enabling people’s “choice, self-determination, and personhood”’.⁸³² Within this context, ‘any form of force or coercion is understood to ultimately undermine the person’s recovery’.⁸³³

No Force First ‘requires that any form of force or coercion is only ever used as a last resort’.⁸³⁴ To achieve this, organisations are instructed to take a whole-of-organisation approach tailored to their own circumstances, and focus on:⁸³⁵

- changing their mission and policy, which should be available to the public and patients, to reflect a commitment to recovery, including recognition of force and coercion as a barrier
- hiring people with lived experience in meaningful employment positions and embracing the value of peer support

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- changing the existing staff culture to embody the commitment to recovery and no force first. This will mean engaging with staff to understand their concerns and potential barriers to reducing force and coercion, and providing relevant training to give staff alternative skills
 - updating hiring processes to identify people who will be compatible with a commitment to No Force First
 - developing compatible policies and procedures to provide clear guidance, include debriefing and other forms of post-incident support, and an opportunity for staff learning and development
 - putting in place strategies and initiatives to develop trusting relationships between staff and patients.

Studies of the No Force First approach have shown reductions in seclusion and physical and chemical restraint in general mental health wards, mental health crisis services and forensic mental health wards.⁸³⁶ Specifically, No Force First ‘resulted in significant initial reduction in the use of restrictive practices’, including a ‘50 per cent reduction in the use of physical and chemical restraint on the pilot wards in the first year’.⁸³⁷ After three years of practice, following its implementation across all wards, ‘there was a 37 per cent reduction in the use of restraint and a 46 per cent reduction in the assault of staff’.⁸³⁸

In addition, a study of the No Force First approach in a crisis centre concluded ‘crisis services can be successfully provided by adopting recovery approaches that do not rely on seclusion and mechanical or chemical restraints’.⁸³⁹

Due to the success of No Force First, ‘a range of other [National Health Service] trusts and other mental health and learning disability services from around the UK and Europe have implemented similar projects’.⁸⁴⁰ In the context of mental health and learning disability settings in the UK, a recent evaluation found a ‘significant 17 per cent reduction in ... physical restraint, in addition to reductions in associated rates of harm sustained and episodes of aggression and violence’.⁸⁴¹ However, the evaluation also found there was ‘a significantly higher prevalence of physical restraint and harm in inpatients on forensic learning disability wards compared to forensic mental health wards’.⁸⁴² This difference remained after the introduction of the No Force First approach.⁸⁴³

Six Core Strategies to Reduce Seclusion and Restraint Use – United States

The Six Core Strategies to Reduce Seclusion and Restraint Use (Six Core Strategies) was developed in 2006 by the National Association of State Mental Health Program Directors in the United States. The Six Core Strategies is ‘designed as a high-level set of key principles and initiatives to guide organisations attempting to reduce use of restrictive practices’.⁸⁴⁴ The Six Core Strategies are ‘framed so they can be applied flexibly to meet the needs of particular service settings, so that bespoke and context-appropriate solutions can be developed to meet the needs of local services and communities’.⁸⁴⁵

The Six Core Strategies proposes a ‘trauma-informed approach’ to services. It can be summarised as follows:⁸⁴⁶

- leadership towards organisational change: including defining and articulating a mission, philosophy of care, guiding values, and developing an implementation, a seclusion and a restraint reduction plan
- use of data to inform practice in an empirical, non-punitive manner
- workforce development to create an environment where policy, procedures and practices are grounded in and directed by a thorough understanding of the effects of trauma and violence, the prevalence of these experiences in people who receive mental health services and the experiences of staff
- use of seclusion and restraint prevention tools, which encompasses a variety of tools and assessments that are integrated into each individual’s treatment stay
- consumer roles in inpatient settings
- debriefing techniques, using knowledge gained from rigorous analysis of seclusion and restraint events to inform policy, procedures and practices to avoid repeats in the future.

Studies of the Six Core Strategies approach have shown reductions in use of restraint and seclusion in specialised mental health organisations, general mental health wards and adolescent psychiatric hospitals.⁸⁴⁷ Relevant studies include the following:⁸⁴⁸

- A 2014 Canadian study in the context of a specialised mental health organisation found a decrease of almost 20 per cent in the total number of restraint incidents, primarily due to a 28 per cent decrease in seclusion incidents.
- An adapted version of Six Core Strategies in the UK led to an average reduction in use of restraint of 22 per cent in adult mental health wards.
- A three-site study in New York showed a decrease of between 62 per cent and 86 per cent in the number of incidents per 1,000-client-days.
- A downward trend in use of restraint and seclusion was also found in a child and adolescent psychiatric hospital in the US.

Importantly, ‘it has been noted that to create coercion- and violence-free environments there must be a major commitment by all staff over an extended period to fully understand and internalise the strategies involved and embrace the changes in facility culture’.⁸⁴⁹

The Six Core Strategies approach was adapted as part of the 2019 Australian College of Mental Health Nurses, Safe in Care, Safe at Work Toolkit for use in Australian mental health contexts.⁸⁵⁰

Notably, the Six Core Strategies approach was also endorsed as part of the National Framework. Jurisdictions agreed that ‘by 2018, all disability service providers for which they or the NDIA have funding responsibilities should implement’ these strategies.⁸⁵¹ The NDIS Regulated Restrictive Practices Guide also highlights these strategies, summarising them as:⁸⁵²

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- person-centred focus
 - leadership towards organisational change
 - use of data to inform practice
 - workforce development
 - use of restraint and seclusion reduction tools
 - debriefing and practice review.

However, there has been no evaluation of the extent to which disability service providers have implemented these strategies or the impact these strategies have had on the use of restrictive practices.

Strengthening the evidence base for restrictive practices

The available evidence base does not support implementing a singular program or approach to reducing and eliminating restrictive practices on a system-wide basis in any setting.

The *Reducing Restrictive Practices* report concluded ‘initiatives need to be tailored to the environment and population cohort and may involve developing bespoke models rather than choosing a single model ‘off the shelf’’.⁸⁵³

Positive behaviour support practices have been shown to have some benefits, but studies are not sufficiently robust to be relied upon universally. Similarly, there have been no evaluations of the implementation of international approaches such as Six Core Strategies in Australian service systems.

The inconclusive nature of current research on restrictive practices in Australia is, perhaps, not surprising. In Public Hearing 6, we found that, since the rollout of the NDIS, overall funding for research on the health and behaviour support needs of people with cognitive disability has been reduced. This limits the opportunities for rigorous research on practices of great importance to people with disability.⁸⁵⁴

The findings from the *Pathway to elimination* report and the *Reducing restrictive practices* report demonstrate the need for high-quality research on ‘what works’ to reduce and eliminate restrictive practices. A stronger evidence base is needed on the impact of positive behaviour support planning and equivalent practices, and their efficacy in reducing and eliminating restrictive practices.

We recommend the National Disability Research Partnership commission a longitudinal study of behaviour support planning and other practices aimed at reducing and eliminating restrictive practices. The study should consider in particular the Six Core Strategies and their impact on reducing and eliminating restrictive practices. The National Disability Research Partnership released its preliminary research agenda in 2022, which recognises it will need to consider our findings and the research gaps we have identified.⁸⁵⁵

The study should focus on the use of restrictive practices in a range of settings, including disability service provision, health, education and justice settings.

This study should be co-designed with and include the diverse voices of people with disability. This includes people with different kinds of disabilities. It also includes LGBTIQ+ people with disability, culturally and linguistically diverse people with disability and First Nations people with disability, noting the limited research on the experiences of these people.⁸⁵⁶ As the *Pathway to elimination* report states, ‘more work needs to be done to fully capture the range of experiences of restrictive practices of diverse, intersectional, disability communities in Australia’.⁸⁵⁷

This study should influence the development of practice in settings in which restrictive practices are used. The findings of the study should be published on completion and interim findings should be published at regular intervals. In light of these findings, the NDIS Commission should review guidance on positive behaviour support and the Six Core Strategies to ensure this guidance is informed by up-to-date research on ‘what works’. State and territory governments should review workforce practices in health, education and justice settings and implement evidence-based strategies to reduce and eliminate the use of restrictive practices. Existing and any newly established Senior Practitioners (in line with Recommendation 6.35) should also consider the study as part of their efforts to promote the reduction and elimination of the use of restrictive practices.

Recommendation 6.38 Strengthening the evidence base on reducing and eliminating restrictive practices

The National Disability Research Partnership should commission a longitudinal study of the impact of positive behaviour support and other strategies to reduce and eliminate restrictive practices. This study should:

- be co-designed with people with disability and relevant experts and professionals from the disability, health, education and justice sectors, to ensure the findings are relevant across a range of settings
- include the experiences and identify the intersecting needs of a broad range of people with disability, such as First Nations people with disability, LGBTIQ+ people with disability, and culturally and linguistically diverse people with disability.

Upon completion, the findings of the study should be made publicly available. Interim findings should be published at regular intervals.

5.8. Restrictive practices data

Improving data collection

The *CRPD* is the only human rights treaty to require the collection of statistics and other data. Article 31 provides, ‘States Parties undertake to collect appropriate information, including statistical and research data, to enable them to formulate and implement policies to give effect to the present Convention’.⁸⁵⁸ We discuss data collection and reporting more generally in Volume 12, *Beyond the Royal Commission*.

As discussed in Section 5.4, there is limited and inconsistent publicly available data on the use of restrictive practices towards people with disability in NDIS, health, education and justice settings. For example, data on the multiple reportable incidents to the NDIS Commission detailing unauthorised use of restrictive practices does not appear to be collated nor analysed in a uniform way. Data on the use of restrictive practices in mental health settings is not disaggregated by disability status.

The National Framework includes specific provisions related to measuring performance and effectiveness of strategies to reduce restrictive practices. These include requiring jurisdictions to report on implementation progress on a biennial basis.⁸⁵⁹ The National Framework provides that work should initially focus on standardised data collection and reporting to establish benchmarks and performance indicators that measure effectiveness in reducing restrictive practices over time.⁸⁶⁰

Restrictive practices data should be collected and published on a regular basis across disability, health, education and justice settings. This should be disaggregated by:

- restraint type, including chemical, physical, mechanical, environmental and seclusion
- disability status
- types of impairment
- age
- gender
- First Nations status
- culturally and linguistically diverse status
- LGBTIQ+ status
- jurisdiction.

The NDIS Commission already collects national data on the use of authorised restrictive practices and unauthorised restrictive practices (as a reportable incident). We discuss the data the NDIS Commission collects and publishes on restrictive practices and make recommendations to address what is missing in Volume 10.

In health, education and justice settings, additional work will be required to collect and publish data that is comparable across different states and territories. The AIHW should work with states and territories to develop consistent definitions and collection methods for data on the use of restrictive practices. The AIHW is well placed to play the collaborative role needed for this task.⁸⁶¹ The AIHW advised the Royal Commission that its:

legislated role is to work with others to develop data standards and collections across health and welfare, and to publish statistics across these areas. It works closely with governments – including Commonwealth, state and territory authorities with health and welfare responsibilities, the Australian Bureau of Statistics (ABS) and other statistical agencies – and with the academic and non-government sector to make this happen.⁸⁶²

Once consistent definitions and data collection methods have been established, state and territory departments responsible for health, education and justice should collect and publish data on restrictive practices annually. This will enable the identification of trends and comparisons across jurisdictions.

AIHW data on the use of restrictive practices in mental health settings is published at the national level as part of the National Mental Health Performance Framework. We note that rates of restraint of people with disability in acute mental health hospital services has been identified as a ‘future measure’ to be included in future reports under Australia’s Disability Strategy 2021–2031 Outcomes Framework.⁸⁶³ The AIHW should ensure it meets its target to release data against this measure by 2025.⁸⁶⁴

Recommendation 6.39 Improving collection and reporting of restrictive practices data

The Australian Institute of Health and Welfare should work with state and territory governments to develop consistent data definitions and collection methods on restrictive practices across all jurisdictions, and align reporting periods. These definitions and collection methods should be finalised by the end of 2024.

Using consistent definitions and collection methods, state and territory governments should collect and publish data on the use of restrictive practices in health, education and justice settings. This data should be collected and published on an annual basis, with publication commencing by the end of 2025 at the latest. Data should identify, to the greatest extent practicable:

- restraint type, including chemical, physical, mechanical, environmental and seclusion
- disability status
- types of impairment
- age

- gender
- First Nations people
- culturally and linguistically diverse people
- people who identify as LGBTIQ+.

Targets and performance indicators

The collection and reporting of data will improve transparency and accountability for the use of restrictive practices. However, this alone is not sufficient to effect real change.

Mental health is the only sector with agreed targets and performance indicators to accompany a commitment to reduce and eliminate restrictive practices. Rates of seclusion and restraint are included in the Key Performance Indicators for Australian Public Mental Health Services. All states and territories collect data on the use of seclusion and restraint in public acute mental health hospitals and provide data for national reporting every year.⁸⁶⁵ Data is collated by the AIHW and reported as part of the Mental Health Services in Australia dataset.⁸⁶⁶

As noted in Section 5.4, AIHW data shows there has been a reduction in the use of seclusion, while the use of physical restraint and mechanical restraints has remained relatively steady.⁸⁶⁷ However AIHW data on the use of restraint and seclusion in mental health settings is not disaggregated by disability status.

There are no similar targets or performance indicators on reducing and eliminating restrictive practices in education, justice or services for people with disability. The establishment of a baseline dataset on the current use of restrictive practices must be accompanied by indicators and targets to measure sector-specific performance and drive practice change.

This was supported by the submission from Dr Nathan Gibson, the Chief Psychiatrist of Western Australia, that ‘data-informed policies and procedures and monitoring, evaluation and state and national reporting’ have contributed to the reduction of seclusion and restraint events in Western Australia.⁸⁶⁸ Dr Gibson acknowledged that the ‘work required to address the issue of seclusion and restraint in the disability sector will be extensive’ and identified data as a barrier which will need to be overcome. He commented:

the lack of data prevents ... monitor[ing] and evaluat[ion] [of] the impact on the use and rate of restrictive policies and practices in each of the key agencies and the development of robust key performance indicators to be used across agencies.⁸⁶⁹

Commitments to reduce and eliminate the use of restrictive practices to date have not been accompanied by specific targets and associated benchmarks. This should be addressed as a matter of priority alongside the establishment of a restrictive practices baseline dataset.

Monitoring progress towards the targets and performance indicators could form part of the role of existing and newly established Senior Practitioners (or equivalent authorities) (see Recommendation 6.35).

Recommendation 6.40 Targets and performance indicators to drive the reduction and elimination of restrictive practices

The Australian Government and state and territory governments should establish sector-specific targets and performance indicators to drive the reduction and elimination of restrictive practices over time. This should be at both the national and state and territory levels for disability, health, education and justice settings. These targets and performance indicators should be established by 1 July 2025 at the latest.

Endnotes

- 1 Lojic Institute, Submission in response to *Disability Royal Commission's Restrictive Practices Issues Paper*, 28 August 2020, ISS.001.00408, p 13.
- 2 *Convention on the Rights of Persons with Disabilities*, opened for signature 30 March 2007, 2515 UNTS 3 (entered into force 3 May 2008).
- 3 Committee on the Rights of Persons with Disabilities, *Concluding observations on the initial report of Australia*, 10th sess, UN Doc No CRPD/C/AUS/CO/1 (21 October 2013), [35].
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- 8 United Nations General Assembly Human Rights Council, *Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment*, 22nd sess, UN Doc A/HRC/22/53, (1 February 2013), p 15 [60].
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- 11 *National Disability Insurance Scheme Act 2013* (Cth) s 9.
- 12 *National Disability Insurance Scheme (Restrictive Practices and Behaviour Support) Rules 2018* (Cth) s 6.
- 13 *National Disability Insurance Scheme (Restrictive Practices and Behaviour Support) Rules 2018* (Cth) s 6(a).
- 14 *National Disability Insurance Scheme (Restrictive Practices and Behaviour Support) Rules 2018* (Cth) s 6(b).
- 15 *National Disability Insurance Scheme (Restrictive Practices and Behaviour Support) Rules 2018* (Cth) s 6(c).
- 16 *National Disability Insurance Scheme (Restrictive Practices and Behaviour Support) Rules 2018* (Cth) s 6(d).
- 17 *National Disability Insurance Scheme (Restrictive Practices and Behaviour Support) Rules 2018* (Cth) s 6(e).
- 18 National Disability Insurance Scheme Quality and Safeguards Commission, *Regulated restrictive practices guide*, October 2020, pp 10–11.
- 19 Transcript, Leanne Dowse, Public hearing 6, 24 September 2020, P-223 [20–21].
- 20 Transcript, Jaqueline Mills, Public hearing 4, 25 February 2020, P-494 [14–16].
- 21 Exhibit 4-19, 'Statement of Jaqueline Mills', 12 February 2020, at [144–45]; Transcript, Jaqueline Mills, Public hearing 4, 25 February 2020, P-504 [22–42].
- 22 Transcript, Claire Spivakovsky, Public hearing 3, 3 December 2019, P-85 [19].
- 23 Transcript, Claire Spivakovsky, Public hearing 3, 3 December 2019, P-85 [18].
- 24 National Disability Services, 'NDS Disability Royal Commission submission: Restrictive practices', Policy News, 2 October 2020. <www.nds.org.au/policy/nds-disability-royal-commission-submission-restrictive-practices>
- 25 Australian Government Department of Social Services, NDIS Quality and Safeguarding Framework, December 2016, p 66.
- 26 Exhibit 6-2, 'Statement of Dr Catherine Franklin', 10 September 2020, at [26].
- 27 Exhibit 6-2, 'Statement of Dr Catherine Franklin', 10 September 2020, at [28]; Transcript, Dr Catherine Franklin, Public hearing 6, 22 September 2020, P-36–37.
- 28 Exhibit 6-2, 'Statement of Dr Catherine Franklin', 10 September 2020, at [28].

29 University of Melbourne, University of Technology Sydney and University of Sydney, *Restrictive practices: A pathway to elimination*, Report prepared for the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, 25 July 2023, pp 6, 82.

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- 131 *National Disability Insurance Scheme (Authorisations) Act 2019* (NT) ss 15(1), 18.
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 166 *Disability Inclusion Act 2018* (SA) s 23G(c)(i).
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 168 *Disability Inclusion (Restrictive Practices – NDIS) Regulations 2021* (SA) regs 4–5.
 169 *Disability Inclusion Act 2018* (SA) s 23O; *Disability Inclusion (Restrictive Practices – NDIS) Regulations 2021* (SA) regs 5(1)(e)(i)–(iii).
 170 *Disability Inclusion (Restrictive Practices – NDIS) Regulations 2021* (SA) reg 8.
 171 *Disability Inclusion Act 2018* (SA) s 23O. See also, *Disability Inclusion Act 2018* (SA) s 23J(1)(d).
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 197 *Disability Act 2006* (Vic) s 3(1) (definition of ‘disability service’).
 198 *Disability Act 2006* (Vic) s 3(1) (definition of ‘disability service provider’).
 199 *Disability Act 2006* (Vic) ss 1(b), 133.
 200 *Disability Act 2006* (Vic) s 3(1) (definition of ‘restrictive practice’).
 201 *Disability Act 2006* (Vic) s 3(1) (definition of ‘mechanical restraint’, ‘physical restraint’, ‘seclusion’).
 202 *Disability Act 2006* (Vic) s 135(1), 145.
 203 *Disability Act 2006* (Vic) ss 136(1)(a)–(d), 136(f). If the restrictive practice is seclusion, additional conditions relating to the provision of bedding and clothing, adequate heating or cooling, food and drink, and toilet arrangements apply: s 136(4).
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 205 *Disability Act 2006* (Vic) ss 135(d), 136(a)–(b).
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270 *Mental Health and Related Services Act 1998* (NT) s 61(1).

271 *Mental Health and Related Services Act 1998* (NT) s 62(16).

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273 *Mental Health and Related Services Act 1998* (NT) ss 61(4), 62(4). In those circumstances, the senior registered nurse must notify the person in charge of the facility and an authorised psychiatric practitioner as soon as practicable following approval: *Mental Health and Related Services Act 1998* (NT) ss 61(5), 62(5).

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6. Involuntary sterilisation

Key points

- Involuntary sterilisation is a surgical procedure performed without voluntary and informed consent that permanently prevents reproduction.
- Involuntary sterilisation of people with disability remains legal in Australia in certain circumstances.
- There is very limited publicly available data on involuntary sterilisation. However, we accept some women and girls with disability are affected by involuntary sterilisation.
- Non-therapeutic sterilisation of people with disability should be prohibited by law unless the person has given their voluntary and informed consent (with support for decision-making if required) or there is a threat to the life of the person if the procedure were not performed.
- Legislative reform is required to achieve the prohibition outlined above.

6.1. Introduction

People with disability can be subjected to a variety of practices that impact their reproductive rights. As we explain in Chapter 5 of this volume, some women with disability are subjected to menstrual suppression to manage ‘behaviours of concern’, rather than for genuine therapeutic purposes. Use of medication to control behaviour, including sexual desire, and suppress menstruation, is classified as a chemical restraint.¹

Through our inquiry we have also been told about women and girls with disability being subjected to involuntary sterilisation.² Involuntary sterilisation is an irreversible surgical procedure that permanently prevents reproduction, performed on a person without their full, free and informed consent. This is sometimes referred to as forced sterilisation. Coerced sterilisation involves situations where a person is pressured, induced or deceived to gain their consent for sterilisation, and they may not understand the full implications of sterilisation.

The *National Plan to End Violence against Women and Children 2022–2032* states that women with disability ‘experience specific forms of gender-based violence including reproductive coercion, forced sterilisation and forced medical interventions’.³

We accept some women and girls with disability experience involuntary sterilisation, despite the limited data on this issue.⁴ We examine involuntary sterilisation in this chapter.

6.2. Key concepts and Australia's position

The position regarding involuntary sterilisation in Australia has been the subject of parliamentary inquiries, Australian Human Rights Commission (AHRC) reports and comment by the United Nations Committee on the Rights of Persons with Disabilities (CRPD Committee).⁵ We have heard evidence about this issue at our public hearings,⁶ and it has also been raised in submissions.⁷

A human rights approach to reproductive abuse

Public hearing 17 examined 'the experiences of women and girls with disability with a particular focus on family, domestic and sexual violence'. Ms Carolyn Frohmader, Executive Director of Women with Disabilities Australia, and Dr Linda Steele, senior lecturer in the Faculty of Law at the University of Technology Sydney, gave evidence on reproductive abuse, including involuntary sterilisation. A key theme of their evidence was that sexual and reproductive rights are human rights, and women with disability should make individual, informed choices about what happens to their bodies.⁸

Evidence at Public hearing 17 showed four explanations that have been used to justify the involuntary sterilisation of women and girls with disability:

- the fear women with disability, particularly those with genetic conditions, will produce children with disability⁹
- the burden of care related to menstrual management,¹⁰ arising from the assumption young women with disability cannot manage menstruation¹¹
- the belief a girl or woman with disability is unlikely to have the capacity to parent so does not need reproductive organs,¹² and is unable to develop the capacity¹³
- a proposition women and girls with disability are particularly vulnerable to sexual abuse, and sterilisation will somehow prevent this from occurring or prevent resulting pregnancy from sexual abuse.¹⁴

The research report *Disability in Australia: Shadows, struggles and successes* links the sterilisation of women with disability to the history of eugenics and social Darwinism.¹⁵ The report describes involuntary sterilisation as being historically practised 'to prevent pregnancy from sexual assault or willing sexual activity as well as menstrual management', with an ongoing influence today.¹⁶ Disability rights activists have focused on the involuntary sterilisation of women and girls with disability in Australia since the early 1990s.¹⁷

The reproductive rights of people with disability are protected under multiple articles of the *Convention on the Rights of Persons with Disabilities (CRPD)*. Article 17 on protecting the integrity of the person provides that '[e]very person with disabilities has a right to respect for his or her physical and mental integrity on an equal basis with others'.¹⁸ Article 23 on respect for home and the family provides, among other things, that '[p]ersons with disabilities, including children, retain their fertility on an equal basis with others'.¹⁹ Article 25 on health includes obligations that States Parties must:

a) Provide persons with disabilities with the same range, quality and standard of free or affordable health care and programmes as provided to other persons, including in the area of sexual and reproductive health and population-based public health programs.²⁰

With respect to women and girls with disability, article 6 provides:

States Parties recognize that women and girls with disabilities are subject to multiple discrimination, and in this regard shall take measures to ensure the full and equal enjoyment by them of all human rights and fundamental freedoms.²¹

Article 6 is cross-cutting, meaning the ‘issues and concerns of women and girls with disability ... must be specifically included in all actions to implement the *CRPD*’.²² It is therefore necessary to consider the particular position of women and girls with disability when interpreting all parts of the *CRPD*, including those parts relevant to sterilisation.

Article 12 of the *CRPD* provides for equal recognition before the law.²³ In this context, this should ensure women and girls with disability are afforded the same rights and legal protections as people without disability regarding decisions to sterilise or suppress menstruation.

However, the CRPD Committee noted in *General comment no. 1 on Article 12 equal recognition before the law*:

women with disabilities are subjected to high rates of forced sterilization, and are often denied control of their reproductive health and decision-making, the assumption being that they are not capable of consenting to sex.²⁴

In its *General comment no.3 on women and girls with disability*, the CRPD Committee stated States Parties should prohibit ‘all forms of forced sterilization, forced abortion and non-consensual birth control’.²⁵ Several United Nations treaty bodies have raised the issue of reproductive rights abuses of people with disability in Australia,²⁶ in particular the involuntary sterilisation of women and girls with disability.²⁷

Emeritus Professor Ron McCallum AO assessed Australia’s compliance with the *CRPD*. In his examination of article 23 on respect for home and the family, he identified reproductive rights as one of the main issues confronting people with disability in Australia.²⁸ He concluded:

it is recommended that, as a matter of some urgency, the Australian, State and Territory governments amend their laws to forbid non-therapeutic sterilization procedures on girls and boys and on adults with disabilities without their full and free consent.²⁹

The position in Australia

Legal authorisation

Involuntary sterilisation of people with disability is legal in Australia in certain circumstances. If the person cannot give consent, the procedure can only be performed if authorised by a court or tribunal with appropriate jurisdiction.

Applications for sterilisation are generally made in one of the following:

- the child welfare jurisdiction of the Federal Circuit and Family Court of Australia
- *parens patriae* jurisdiction of state and territory superior courts, which is generally exercised in child care and protection or mental health-related matters
- the guardianship and substitute decision-making jurisdiction of state and territory tribunals, where authorised by relevant law.

Following *Secretary of the Department of Health and Community Services v JWB & SMB (Marion's case)*,³⁰ which we discuss below, parents or guardians of a child can only authorise the sterilisation of the child in cases where it is therapeutic. The majority in *Marion's case* drew a distinction between:³¹

- **therapeutic sterilisation** – procedures where permanent infertility is either ‘a by-product of surgery appropriately carried out to treat some malfunction or disease’ or an incidental result of surgery performed to cure a disease or correct some malfunction
- **non-therapeutic sterilisation** – procedures that fall outside therapeutic sterilisation, such as to manage menstruation or prevent the risk of conception.

Marion's case is authority for the proposition that there is a distinction between ‘therapeutic’ and ‘non-therapeutic’ sterilisation, with court authorisation required for ‘non-therapeutic’ procedures.³² *Marion's case* confirmed authorisations of this nature fall within the Family Court’s child welfare jurisdiction.³³

Child welfare jurisdiction

In *Marion's case*, the High Court of Australia considered the issue of sterilisation of a girl with disability.³⁴ At the time of the appeal to the High Court, Marion, a girl with intellectual disability, was 14 years old. Marion’s parents had applied to the Family Court of Australia for an order authorising a hysterectomy and ovariectomy to be performed on Marion. The hysterectomy was proposed to prevent ‘pregnancy and menstruation with its psychological and behavioural consequences’ and the ovariectomy was ‘to eliminate consequential stress and behavioural responses’.³⁵

The majority of the High Court held court authorisation was required for sterilisation to be performed on a child who lacked capacity to consent, where the procedure was for

non-therapeutic purposes. Their Honours said there are features of sterilisation and factors involved in the decision to authorise it 'to ensure the best protection of the interests of a child ... should not come within the ordinary scope of parental power to consent to medical treatment'.³⁶

In considering the scope of parental power to consent medical decisions on behalf of a child, their Honours said the approach of the House of Lords in *Gillick v West Norfolk AHA*³⁷ should be followed in Australia.³⁸ This incorporated into Australian common law the principle known as 'Gillick competence', which their Honours explained as follows:

parental power to consent to medical treatment on behalf of a child diminishes gradually as the child's capacities and maturity grow and that this rate of development depends on the individual child.

...

A minor is, according to this principle, capable of giving informed consent when he or she 'achieves a sufficient understanding and intelligence to enable him or her to understand fully what is proposed'.³⁹

When considering whether to authorise sterilisation, the court is required to decide whether, in the circumstances of the particular case, sterilisation is:⁴⁰

- in the child's best interests, and
- 'a step of last resort'.

In considering the issue of sterilisation in this context, the majority emphasised they were not referring to sterilisation that resulted from 'surgery appropriately carried out to treat some malfunction or disease'.⁴¹ They continued:

We hesitate to use the expressions 'therapeutic' and 'non-therapeutic', because of their uncertainty. But it is necessary to make the distinction, however unclear the dividing line may be.

As a starting point, sterilization requires invasive, irreversible and major surgery. But so do, for example, an appendectomy and some cosmetic surgery, both of which, in our opinion, come within the ordinary scope of a parent to consent to. However, other factors exist which have the combined effect of marking out the decision to authorise sterilization as a special case. Court authorization is required, first, because of the significant risk of making the wrong decision, either as to a child's present or future capacity to consent or about what are the best interests of a child who cannot consent, and secondly, because the consequences of a wrong decision are particularly grave.⁴²

In 1995, in *P and P and Legal Aid Commission of NSW (Re P)*, the Full Family Court applied the legal test for court authorised sterilisation of a girl with intellectual disability.⁴³ It found that sterilisation may be justified in certain circumstances to prevent pregnancy, to prevent the consequences of sexual abuse, to remedy problems associated with menstruation or to ease

the burden on carers of the child, but it is a step of last resort. The court specifically rejected the application of a ‘but for’ test (namely, would the procedure be performed but for the disability), stating:

the responsibility to assess the child’s best interests is not furthered by compartmentalising one or more of her attributes and measuring the appropriateness of the proposed treatment against a hypothetical child. ... If applied literally the test would mean that sterilisation could never be authorised other than for therapeutic medical reasons, because one would never contemplate the sterilisation of an intellectually normal 17 year old other than for such reasons.⁴⁴

In *Re P*, the Full Court considered the appointment of separate representatives for children in ‘sterilisation and other *parens patriae* cases’.⁴⁵ The Court considered the issue of ‘Gillick competence’ and explained there is a ‘primary duty’ to:

establish whether the child in question is ‘Gillick competent’ ... because neither the parent nor the separate representative can consent to the procedure if the child is not ‘Gillick competent’.⁴⁶

Following the merger of the Family Court of Australia and Federal Circuit Court of Australia in 2021, the *Federal Circuit and Family Court of Australia (Family Court) Rules 2021* (Cth) set out the process that must be followed when an order authorising sterilisation is sought. The rules adopt the language in *Marion’s case* and apply to applications ‘for an order authorising a major medical procedure for a child that is not for the purpose of treating a bodily malfunction or disease’.⁴⁷ Evidence in support of an application must satisfy the court that the ‘proposed medical procedure is in the best interests of the child’.⁴⁸

The AHRC has often acted as an *amicus curiae* or impartial advisor in court in cases concerning the sterilisation of young women with disability, including in *Marion’s case*.⁴⁹

Parens patriae jurisdiction

In Chapter 2 of this volume, we explain how judges of superior courts are empowered to make decisions for a person who lacks capacity in the exercise of what is known as the *parens patriae* jurisdiction.⁵⁰ In principle, the court exercises this power with the aim of protecting people who are deemed to lack capacity.⁵¹ This jurisdiction applies to both children and adults.

Re a Patient Fay concerned whether Fay, a 19-year-old Aboriginal woman with intellectual disability, had capacity to refuse medical treatment. In that case, a local health district sought to invoke the *parens patriae* jurisdiction of the Supreme Court of New South Wales. In considering the application, Sackar J observed ‘the *parens patriae* jurisdiction is ancient, wide-ranging and far-reaching’.⁵² His Honour explained the power is:

generally to be exercised only in exceptional cases and with considerable caution. In the case of an adult, this caution is especially important because care should always be taken to ensure that there is no interference unlawfully in the free will of a capable individual.⁵³

Substitute decision-making

Sterilisation of adults with disability is governed by state and territory guardianship and substitute decision-making regimes.⁵⁴ These regimes only apply when a person is found to lack capacity to make decisions. In some instances, these regimes also apply to children. On 6 May 2009, the Australian Guardianship and Administration Council (AGAC) released its Protocol for Special Medical Procedures (Sterilisation) (AGAC protocol). This protocol was:

designed to assist the various Australian guardianship tribunals in exercising this power, and to promote consistency across the jurisdictions when dealing with an application for the sterilisation of a person.⁵⁵

However, there remains variation between the states and territories for the threshold applied to authorising sterilisations.

New South Wales has the highest threshold. There, sterilisation is categorised as ‘special treatment’, which includes ‘any treatment that is intended, or is reasonably likely, to have the effect of rendering permanently infertile the person on whom it is carried out’.⁵⁶ The tribunal must not consent to special treatment unless it is satisfied the treatment is necessary ‘to save the patient’s life’ or ‘to prevent serious damage to the patient’s health’.⁵⁷

In Queensland and South Australia, the focus is on whether sterilisation is medically or therapeutically necessary.⁵⁸ In those states, sterilisation may also be authorised for contraceptive and menstrual management purposes.⁵⁹

Tasmania, Western Australia and the Australian Capital Territory apply ‘best interests’ tests.⁶⁰ In Tasmania and the Australian Capital Territory, the relevant tribunals must consider:⁶¹

- the wishes of the person so far as they can be ascertained
- the consequences if treatment is not carried out
- the available alternatives to treatment
- whether it can be postponed because better treatment may become available and in Tasmania only, because the person may become capable of giving consent.

The Victorian position attempts to understand the person’s will and preference. When considering whether to consent to a ‘special medical procedure’, including a procedure intended to or reasonably likely to cause permanent infertility, the tribunal must be satisfied the person would consent if they had capacity to consent.⁶² If the person has not expressed their preferences, the tribunal must consider the person’s expressed or inferred values.⁶³ If the tribunal is unable to ascertain the person’s preferences or values, the tribunal:⁶⁴

- must be satisfied the special medical procedure will promote the personal and social wellbeing of the person, having regard to the need to respect the person's individuality
- consider the likely effects and consequences of the special medical procedure, including the likely effectiveness of the procedure
- consider whether there are any alternatives, including refusing the special medical procedure, that would better promote the person's personal and social wellbeing.

In the Northern Territory, the tribunal must act in accordance with its 'guardianship principles'.⁶⁵ There, 'restricted health care' includes sterilisation unless it is a 'consequence of health care action that is taken primarily to treat' an illness or injury.⁶⁶

Available data

Data on sterilisation procedures in Australia is very limited. Data on sterilisations of children authorised by courts is not publicly available, as these decisions are often made in a closed court. Only some jurisdictions publish decisions involving adults, with those decisions being de-identified. Dr Steele said transparency around decisions would better protect women and girls from violence.⁶⁷

As discussed in Chapter 3 of Volume 3, *Nature and extent of violence, abuse, neglect and exploitation*, AGAC has released the *Australian Sterilisation Data Report* on an annual basis since 2015.⁶⁸ The report contains data on tribunal and board-approved medical procedures that result in sterilisation of adults with cognitive disability. It does not distinguish between men and women and does not include information about sterilisation of people under 18 years. The most recent report records that 14 adult sterilisation procedures were approved between 1 July 2021 and 30 June 2022.⁶⁹ Five were in New South Wales, five were in Queensland, and two occurred in Western Australia and Victoria respectively. Other states and territories did not approve any sterilisation procedures during this period.

Dr Steele said the quantitative data currently released does not solve the issues around lack of transparency.⁷⁰ She explained:

to simply have those numbers is not giving us that depth of detail about what kinds of assumptions and ideas and knowledge around women and girls with disability are held by individual judges or enabled by psychological expertise or legal principles. We're not getting that level of information and that's really important to have.⁷¹

She said transparency was necessary to understand that 'these decisions are allowing violence to occur, they are not protecting women and girls from violence'.⁷²

In Public hearing 17, Ms Frohmader and Dr Steele gave evidence on the gendered and ableist attitudes about women and girls with disability that result in denial of their reproductive and sexual rights.⁷³ They explained these attitudes have resulted in women and girls with disability being denied reproductive and sexual rights.⁷⁴ Dr Steele said:

we can think of the many other personal care and support needs that women and men and boys and girls and people of any gender with disability might need across their lives. There is no explicit legal option or legal doctrine around enabling various other bodily processes and bodily organs and parts to be removed. There is something particular about menstruation and sexuality of women and girls with disability that makes this even possible for us to legally consider.⁷⁵

Data on sterilisation of people with disability in Australia is limited by the different legal tests for when sterilisation can be authorised in different jurisdictions.⁷⁶ Dr Steele explained:

In New South Wales, for example, the tribunal needs to be satisfied the treatment is the most appropriate form of treatment for promoting wellbeing and it's necessary to save life or prevent serious damage to health.

In contrast, in Queensland and South Australia ... sterilisation can be authorised by a tribunal where it's medically necessary or where it's necessary for contraception or menstrual purposes where other interventions are not suitable. There is a vast range in terms of when sterilisation can be authorised.⁷⁷

Experiences of sterilisation and denial of reproductive rights

We have received a small number of accounts of involuntary sterilisation, provided through submissions and private sessions. People with disability who are isolated or have limited communication may find it difficult or even impossible to voice their experiences of involuntary sterilisation. In addition, the accounts we have received describe reproductive abuse in settings and relationships that are difficult to monitor, such as by medical practitioners, intimate partners, parents, and in mental health inpatient units.⁷⁸

In Public hearing 26, 'Charlotte' told us of her experiences.⁷⁹

Forced termination and sterilisation: 'Charlotte'

At Public hearing 26, 'Homelessness, including experience in boarding houses, hostels and other arrangements', Charlotte described her time in a boarding house in the 1980s and 1990s. After experiencing and witnessing neglect, violence and abuse at the boarding house, Charlotte told the ex-boyfriend of a manager that she did not like living there. He told her she could live with him, but, in Charlotte's words, 'he just wanted a slave'.⁸⁰

Charlotte found out she was pregnant. She explained the doctor 'had the letter all written out for me to go to hospital ... saying that I was to have a termination'.⁸¹

Charlotte said, at hospital, she was forced to terminate her pregnancy and to be sterilised.⁸² Charlotte said she was threatened with a mental health order if she did not agree to have the termination. She told us:

I might not have wanted to have a child in that way, but I regret not being given the option. I did not have a normal life after that termination.⁸³

Charlotte said that not long after the termination, she overdosed because she wanted to die. She was sent to a hospital under a mental health order, and then back to the boarding house to live.⁸⁴

We received submissions about women with disability being sterilised in the context of sexual assault while living in institutions. In one submission, a woman with disability told us she lived in an institution where she witnessed and was subjected to severe violence and abuse. She said that, after being raped, ‘they tried to sterilise me’ when she gave birth to her son. She also told us about a woman who was raped, had her pregnancy terminated and was sterilised.⁸⁵

In another submission, the brother of a woman with intellectual disability told us about his sister, who was in the care of an institution from the time she was a baby. He said when she was 16 and living at an adult institution, he and his parents witnessed and heard about the sexual assault of residents by other residents and nurses or guards. He said his parents sought to have his sister sterilised, but this was refused. He said the people with disability who lived in institutions ‘were not treated as people’.⁸⁶

We also heard about sterilisation sought by parents of a girl with disability living at home. In a submission, a woman with disability described how, when she was 10, her parents paid a gynaecologist ‘off the books’ to perform a hysterectomy on her. She later wanted to have children with her husband, but they were unable to do so.⁸⁷

We were also told about involuntary sterilisation performed by medical practitioners without appropriate authorisation. ‘Merindah’, an autistic First Nations woman, described experiencing sterilisation without her informed consent in a surgery organised by her treating psychiatrist. She said that, through her psychiatric treatment, she had come to believe her parents were terrible people and that as she had the same mental health condition as them, she would be:

an awful terrible mother and that I should not have a right to have children. That I would only pass on something awful just like I believed that my parents had done to me.⁸⁸

For this reason, she agreed to what she believed was:

reversible sterilisation of having my tubes clipped (tied) ... I was to learn a decade later that my fallopian tubes had been completely removed, making it a permanent sterilisation ... I never consented to having my tubes removed.⁸⁹

Merindah described a lack of accountability and oversight in her treatment, which allowed her doctor to abuse her.⁹⁰

6.3. Need for reform

Calls for reform

Australian Human Rights Commission reports

In 1997, the AHRC released *The sterilisation of girls and young women in Australia: a legal, medical and social context*. It was commissioned by the inaugural Disability Discrimination

Commissioner, Elizabeth Hastings.⁹¹ It concluded ‘the law has failed to protect significant numbers of children from significant abuse of their fundamental human right to bodily integrity’.⁹² The report, which was updated in 2001, recommended urgent legal reform on the sterilisation of children at the national, state and territory levels. It also recommended that service providers be given information about fertility and menstrual management, and about the law on the sterilisation of children.⁹³

In 2020, the AHRC highlighted the ‘limited progress’ the Australian Government had made ‘in addressing the sterilisation of persons with disabilities without consent’.⁹⁴ The AHRC subsequently released *Ensuring health and bodily integrity*, a report on the medical treatment of intersex people in Australia, including procedures that result in sterilisation. The report recommended obtaining informed consent and engaging in medical intervention on intersex children only where urgently required to avoid serious harm.⁹⁵

2013 Senate Inquiry

In 2013, the Senate Community Affairs References Committee released the reports, *Involuntary or coerced sterilisation of people with disabilities in Australia* and *Involuntary or coerced sterilisation of intersex people in Australia*.⁹⁶

The Senate Committee recommended that laws and procedures may permit the sterilisation of people with disability in cases where there is no legal capacity for consent. It recommended that nationally uniform legislation should be adopted to regulate, rather than prohibit, the involuntary sterilisation of people with disability.⁹⁷ This recommendation was in opposition to the views of disabled people’s organisations,⁹⁸ the AHRC⁹⁹ and a number of United Nations Committees.¹⁰⁰ The proposed changes have not been implemented.

The Senate Committee also recommended data about adult and child sterilisation cases be recorded and reported in the same way in each jurisdiction.¹⁰¹ That recommendation was implemented in part through the AGAC *Australian Sterilisation Data Report*, although the data is limited to cases involving adults.

More recently, the Committee noted concerns regarding women with disability’s self-determination in relation to ‘forced or coerced medical interventions, such as sterilisation, contraception, and abortion’.¹⁰²

Further work is needed

In the years since *Marion’s case*, some academic analysis has suggested decisions on the issue of sterilisation have not given ‘full effect to its promise’, the legal requirements of *Marion’s case* have not always been followed and the distinction between therapeutic and non-therapeutic sterilisations has been blurred.¹⁰³ Notwithstanding the High Court majority’s comments in *Marion’s case* about the need for legislative reform,¹⁰⁴ and an attempt by the former Standing Committee of Attorneys-General to seek a national framework on the sterilisation of children,¹⁰⁵ there remains no uniform national framework on sterilisation.

Legislation should make clear that preventing sexual abuse, menstrual management, easing the burden on carers, and perceived incapacity for parenthood do not justify sterilisation. Non-therapeutic sterilisation of people with disability should be prohibited by law except where there is a threat to the life of the person with disability if the procedure is not performed or the procedure is necessary for a genuine therapeutic purpose, including to prevent serious damage to a person's health. Consistent with *Marion's case*, sterilisation should only be 'a step of last resort'.

Prohibition of sterilisation of people with disability

Recommendation 6.41 calls on the Australian Government and state and territory governments to amend or enact laws prohibiting non-therapeutic sterilisation of people with disability.

We recognise that people with disability, like people without disability, may want or need a procedure resulting in sterilisation for a variety of therapeutic reasons. These may include gender affirmation or management of a condition such as endometriosis. If there is a genuine health reason for sterilisation, then people with disability should have equitable and equal access to those services. Our recommendation is not intended to prevent procedures carried out for therapeutic reasons.

Recommendation 6.41 provides that adults with disability who can and do consent to a sterilisation procedure, with support for decision-making if required, should not be prevented from undergoing the procedure. Requiring support to make this decision should not be an impediment, and people with disability who require support should be provided with it. We discuss 'decision-making ability' and support for decision-making further in Chapter 2 of this volume.

Recommendation 6.41 contains a further exception to the prohibition. People with disability have the right to the highest attainable standard of health without discrimination. Accordingly, the recommendation provides that, notwithstanding the prohibition on non-therapeutic sterilisation, it may occur if there is a threat to the life of the person with disability were the procedure not performed.

These provisions seek to ensure that a person with disability who, for example, experiences terrible pain, where alternative therapy has been tried, but is deemed unable to consent to a medical procedure, can undergo a procedure that will result in sterilisation. This should only occur as a last resort and in extraordinary circumstances.

Data collection and legislative review

Recommendation 6.41(d) provides that AGAC should improve its collation and publication of data on the sterilisation of people with disability in Australia. As noted above, currently AGAC collects data on tribunal-approved medical procedures that result in sterilisation of adults with cognitive disability. We recommend the data AGAC collects should be expanded beyond adults or people with cognitive disability to include any authorisations of sterilisation made by a court as well as by a tribunal. This includes de-identified data on cases in the child welfare jurisdiction.

Recommendation 6.41(c) also provides that AGAC's collation and publication should include data on applications, the reasons for applications, and approvals of sterilisation of people with disability, that occur through:

- the child welfare jurisdiction of the Federal Circuit and Family Court of Australia
- the common law *parens patriae* jurisdiction of state and territory superior courts
- state and territory guardianship and administration bodies.

In Recommendation 6.41(d), we recommend a five-yearly review of legislation enacted or amended to prohibit the sterilisation of people with disability. Reviews should consider the data published annually according to recommendation 6.41(c), and involve an analysis of this data to identify trends over time. Reviews should include recommendations as appropriate with the aim of strengthening the human rights protections for people with disability and avoiding consequences which hamper reproductive autonomy. Reviews should also consider any further amendments that may be needed in relation to the rights and best interests of children with disability.

Recommendation 6.41 Legislative prohibition of non-therapeutic sterilisation

- a. All jurisdictions should amend or enact legislation prohibiting non-therapeutic procedures resulting in permanent sterilisation of people with disability, except where:
 - there is a threat to the life of the person with disability were the procedure not performed or
 - the person with disability is an adult and has given voluntary and informed consent to the procedure, with support for decision-making if required.
- b. All jurisdictions should amend or enact legislation in accordance with paragraph a. by the end of 2024.
- c. The Australian Guardianship and Administrative Council (AGAC) should expand its annual collation and publication of data on the sterilisation of people with disability. This data should include the number of applications, reasons for applications, reasons for the outcomes of applications and the number of approvals to conduct a sterilisation procedure.

Where this does not already occur, the data should be collected and provided to AGAC annually by:

- the Federal Circuit and Family Court of Australia
- state and territory superior courts
- state and territory guardianship and administration bodies.

The data should be de-identified, as appropriate. It should be disaggregated, to the greatest extent possible, by:

- disability status
 - types of impairment
 - age
 - gender
 - First Nations people
 - culturally and linguistically diverse people
 - people who identify as LGBTIQ+.
- d. A review of legislation enacted or amended according to paragraph a. of this recommendation should be conducted every five years, in light of the data published according to paragraph c. This review should aim to strengthen protections for people with disability and avoid consequences which hamper reproductive autonomy.

Endnotes

- 1 NDIS Quality and Safeguards Commission, Regulated Restrictive Practices Guide, October 2020, pp 10–11.
- 2 While the Senate Community Affairs References Committee received Medicare data in 2013 showing vasectomies being performed on young men and boys aged 15–24 between 2003–2012, we have received no further evidence on the involuntary sterilisation of boys and men with disability. Senate Community Affairs References Committee, *Involuntary or coerced sterilisation of intersex people in Australia*, July 2013, p 159 [7.22].
- 3 Australian Government Department of Social Services, *National Plan to End Violence against Women and Children 2022–2032*, October 2022, p 36.
- 4 Women with Disabilities Australia, Submission in response to *Violence and abuse at home issues paper*, April 2021, ISS.001.00635, p 18; Carolyn Frohmader for Women with Disabilities Australia, Submission to the Senate Community Affairs References Committee inquiry into the involuntary or coerced sterilisation of people with disabilities in Australia: ‘Dehumanised: The forced sterilisation of woman and girls with disabilities in Australia’, March 2013, p 28; Laura Elliott, ‘Victims of violence: The forced sterilisation of women and girls with disabilities in Australia’, (2017), vol 6(3), *Laws, MDPI*, p 1.
- 5 Senate Community Affairs References Committee, *Involuntary or coerced sterilisation of people with disabilities in Australia*, July 2013; Senate Community Affairs References Committee, *Involuntary or coerced sterilisation of intersex people in Australia*, October 2013; Susan M Brady & Sonia Grover, *The sterilisation of girls and young women in Australia: a legal, medical and social context*, for the Disability Discrimination Commissioner, December 1997; Australian Human Rights Commission, *Third Universal Periodic Review submission*, 2020, [25]; Committee on the Rights of Persons with Disabilities, *Concluding observations on the combined second and third periodic reports of Australia*, 22nd sess, UN Doc CRPD/C/AUS/CO/2-3, (15 October 2019), [33].
- 6 Public hearing 17, ‘The experiences of women and girls with disability with a particular focus on family, domestic and sexual violence’; Public hearing 26, ‘Homelessness, including experience in boarding houses, hostels and other arrangements’.
- 7 Women with Disabilities Australia, Submission in response to *Violence and abuse at home issues paper*, April 2021, ISS.001.00635; Queensland Law Society, Submission in response to *Restrictive practices issues paper*, September 2020, ISS.001.00439; Family Planning NSW, Submission, 18 March 2020, SUB.001.00154; Submission by Advocacy Tasmania, Submission in response to *Health care for people with cognitive disability issues paper*, ISS.001.00238; Submission by Leadership Plus, Submission in response to *Violence and abuse at home issues paper*, ISS.001.00568; Australian Human Rights Commission, Submission, 23 December 2022, SUB.001.03203, p 30.
- 8 Transcript, Carolyn Frohmader, Public hearing 17 (Part 1), 14 October 2021, P-81 [20] – P-100 [25]; Transcript, Linda Steele, Public hearing 17 (Part 1), 14 October 2021, P-81 [20] – P-100 [25].
- 9 Transcript, Carolyn Frohmader, Public hearing 17 (Part 1), 14 October 2021, P-85 [32–36].
- 10 Transcript, Carolyn Frohmader, Public hearing 17 (Part 1), 14 October 2021, P-85 [43–45].
- 11 Transcript, Carolyn Frohmader, Public hearing 17 (Part 1), 14 October 2021, P-86 [9–11].
- 12 Transcript, Carolyn Frohmader, Public hearing 17 (Part 1), 14 October 2021, P-87 [18–21].
- 13 Transcript, Carolyn Frohmader, Public hearing 17 (Part 1), 14 October 2021, P-87 [27–30].
- 14 Transcript, Carolyn Frohmader, Public hearing 17 (Part 1), 14 October 2021, P-87 [40] – P-88 [15].
- 15 Lorna Hallahan & Flinders University, *Disability in Australia Shadows, struggles and successes: A usable socio-cultural history of disability in Australia*, Report prepared for the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, November 2021, pp 39–41.
- 16 Lorna Hallahan & Flinders University, *Disability in Australia Shadows, struggles and successes: A usable socio-cultural history of disability in Australia*, Report prepared for the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, November 2021, p 41.
- 17 Australian Government, *Agents of Our Own Destiny: Activism and the road to the Disability Royal Commission*, Report prepared for the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, November 2021, p 9.

- 18 *Convention on the Rights of Persons with Disabilities*, opened for signature 30 March 2007, 2515 UTS 3 (entered into force 3 May 2008), art 17.
- 19 *Convention on the Rights of Persons with Disabilities*, opened for signature 30 March 2007, 2515 UTS 3 (entered into force 3 May 2008), art 23 1 (c).
- 20 *Convention on the Rights of Persons with Disabilities*, opened for signature 30 March 2007, 2515 UTS 3 (entered into force 3 May 2008), art 25 (a). See also art 15, 17.
- 21 *Convention on the Rights of Persons with Disabilities*, opened for signature 30 March 2007, 2515 UNTS 3 (entered into force 3 May 2008), art 6 (1).
- 22 Rosemary Kayess & Therese Sands, *Convention on the Rights of Persons with Disabilities: Shining a light on Social Transformation*, Report prepared for the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, September 2020, p 35.
- 23 *Convention on the Rights of Persons with Disabilities*, opened for signature 30 March 2007, 2515 UTS 3 (entered into force 3 May 2008), art 12 (4).
- 24 Committee on the Rights of Persons with Disabilities, *General comment no. 1 (2014) Article 12: Equal recognition before the law*, CRPD/C/GC/1, (11 April 2014), [35].
- 25 Committee on the Rights of Persons with Disabilities, *General Comment No 3: on women and girls with disabilities*, UN Doc CRPD/C/GC/3 (25 November 2016), [63a].
- 26 Committee on the Rights of the Child, *Consideration of reports submitted by States parties under article 44 of the Convention: Convention on the Rights of the Child: concluding observations: Australia*, 60th sess, UN Doc CRC/C/AUS/CO/4, (29 May–15 June 2012) [46–47], [57–58]; United Nations General Assembly Human Rights Council *Draft report of the Working Group on the Universal Periodic Review: Australia*, A/HRC/WG.6/10/L. 8, (31 January 2011), [86.39]; Committee on the Elimination of Discrimination against Women, *Concluding observations of the Committee on the Elimination of Discrimination against Women: Australia*, CEDAW/C/AUS/CO/7, (12–30 July 2010); Committee on the Rights of the Child, 40th sess, *Consideration of reports submitted by states parties under article 44 of the Convention: Convention on the Rights of the Child: Concluding Observations: Australia*, CRC/C/15/Add.268 (20 October 2005) [45–46 (e)].
- 27 Committee on the Rights of Persons with Disabilities, *Concluding observations on the combined second and third periodic reports of Australia*, 22nd sess, UN Doc CRPD/C/AUS/CO/2-3, (15 October 2019), [33].
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- 29 Ron McCallum, *The United Nations Convention on the Rights of Persons with Disabilities: An Assessment of Australia's Level of Compliance*, Report prepared for the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, October 2020, p 82.
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- 38 *Secretary of the Department of Health and Community Services v JWB & SMB (Marion's case)* [1992] HCA 15, (1992) 175 CLR 218, pp 237–239 per Mason CJ, Dawson, Toohey and Gaudron JJ.
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40 *Secretary of the Department of Health and Community Services v JWB & SMB (Marion's case)*
 [1992] HCA 15, (1992) 175 CLR 218, p 259 per Mason CJ, Dawson, Toohey and Gaudron JJ.

41 *Secretary of the Department of Health and Community Services v JWB & SMB (Marion's case)*
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 Community Services v JWB & SMB (Marion's case)* [1992] HCA 15, (1992) 175 CLR 218; *P and P
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Act 1998 (NSW), s 175; *Guardianship of Adults Act 2016* (NT), ss 4, 8, 23; *Guardianship and
 Administration Act 2000* (Qld), s 70 and Chapter 5A; *Guardianship and Administration Act*
1993 (SA), s 61; *Guardianship and Administration Act 1995* (Tas), ss 3, 45; *Guardianship and
 Administration Act 2019* (Vic), ss 140–149; *Guardianship and Administration Act 1990* (WA),
 ss 56–63.

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 (Sterilisation), May 2009, p 4.

56 *Guardianship Act 1987* (NSW), s 33(1).

57 *Guardianship Act 1987* (NSW), s 45.

58 *Guardianship and Administration Act 2000* (Qld), s 70(1)(a)(i); *Guardianship and Administration
 Act 1993* (SA), s 61(2)(a).

59 *Guardianship and Administration Act 2000* (Qld), s 70(1)(a)(ii) and (iii); *Guardianship and
 Administration Act 1993* (SA), s 61(2)(b).

60 *Guardianship and Administration Act 1995* (Tas), s 45(1)(c) and 45 (2), *Guardianship and
 Administration Act 1990* (WA), s 63(1); *Guardianship and Management of Property Act 1991*
 (ACT), s 70(1).

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 TASCAT 105 for a recent illustration of the approach in Tasmania.

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64 *Guardianship and Administration Act 2019* (Vic), s 145(3).

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66 *Guardianship of Adults Act 2016* (NT), ss 8, 23.

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Appendices

Appendix 6A – Data on guardianship and administration

Applications and orders for administration and guardianship across jurisdictions

New South Wales

In New South Wales, the Guardianship Division of the NSW Civil and Administration Tribunal (NCAT) deals with guardianship matters.

For the year 2021–22, NCAT received 4,590 applications for guardianship orders and 3,394 applications for financial management orders.¹ NCAT appointed the NSW Public Guardian in 50 per cent of the 4,413 initial guardianship orders made and the NSW Trustee and Guardian (NSW Trustee) in 51 per cent of the 3,306 initial administration orders made.² Table 6A.1 shows a consistent increase in applications for guardianship since the year 2016–2017.

Table 6A.1: Overview of applications and public appointments for guardianship and financial management in New South Wales between 2016 and 2022

Year	Guardianship applications	Public / private appointments	Financial management applications	Public / private appointment
2021–2022 ^a	4,590 received 4,413 finalised	49.7% Public Guardian 48.8% private guardian 1.5% joint private guardian and Public Guardian	3,394 received 3,306 finalised	49% NSW Trustee 51% private financial managers
2020–2021 ^b	4,569 received 4,422 finalised	54% Public Guardian 44% private guardian 2% joint private guardian and Public Guardian	3,525 received 3,485 finalised	54% NSW Trustee 46% private financial managers

Year	Guardianship applications	Public / private appointments	Financial management applications	Public / private appointment
2019–2020 ^c	4,014 received 3,936 finalised	57% Public Guardian 41% private guardian 2% joint private guardian and Public Guardian	3,335 received 3,265 finalised	52% NSW Trustee 48% private financial managers
2018–2019 ^d	3,666 received 3,674 finalised	56.5% Public Guardian 41.8% private guardian 1.7% joint private guardian and Public Guardian	3,166 received 3,157 finalised	52.4% NSW Trustee 47.6% private financial managers
2017–2018 ^e	3,229 received 3,312 finalised	57.7% Public Guardian 40.4% private guardian 1.9% joint private guardian and Public Guardian	2,897 received 3,003 finalised	52.6% NSW Trustee 47.4% private financial managers
2016–2017 ^f	3,141 received 3,137 finalised	59% Public Guardian 39.5% private guardian 1.5% joint private guardian and Public Guardian	2,884 received 2,965 finalised	52% NSW Trustee 48% private financial managers

^a NSW Civil and Administrative Tribunal, *NCAT Annual report 2021–2022*, p 43.

^b NSW Civil and Administrative Tribunal, *NCAT Annual report 2020–2021*, p 42.

^c NSW Civil and Administrative Tribunal, *NCAT Annual report 2019–2020*, p 45.

^d NSW Civil and Administrative Tribunal, *NCAT Annual report 2018–2019*, pp 39–40.

^e NSW Civil and Administrative Tribunal, *NCAT Annual report 2017–2018*, p 44.

^f NSW Civil and Administrative Tribunal, *NCAT Annual report 2016–2017*, p 44.

NCAT also reports data on the legal representation of parties and attendance of interpreters in guardianship and administration proceedings (see Table 6A.2).

Table 6A.2: Overview of legal representation and interpreting services provided in applications in New South Wales between 2016 and 2022

Year	One or more parties legally represented in applications	Interpreters provided
2021–2022 ^a	Granted 215 requests for legal representation and appointed 562 separate representatives (one or more parties were legally represented in 5.2% of applications)	1,632 interpreters in 62 languages arranged to attend hearings
2020–2021 ^b	Granted 222 requests for legal representation and appointed 601 separate representatives (one or more parties were legally represented in 6% of applications)	953 interpreters in 57 languages arranged to attend hearings
2019–2020 ^c	Granted 163 requests for legal representation and appointed 477 separate representatives (one or more parties were legally represented in 5% of applications)	922 interpreters in 50 languages arranged to attend hearings
2018–2019 ^d	Granted 186 requests for legal representation and appointed 439 separate representatives (one or more parties were legally represented in 5.3% of applications)	1,201 interpreters in 55 languages arranged to attend hearings
2017–2018 ^e	Granted 190 requests for legal representation and appointed 370 separate representatives (one or more parties were legally represented in 5.4% of applications)	1,166 interpreters in 60 languages arranged to attend hearings
2016–2017 ^f	Granted 182 requests for legal representation and appointed 309 separate representatives (one or more parties were legally represented in 4.6% of applications)	739 interpreters in 57 languages arranged to attend hearings

^a NSW Civil and Administrative Tribunal, *NCAT Annual report 2021–2022*, p 43.

^b NSW Civil and Administrative Tribunal, *NCAT Annual report 2020–2021*, p 42.

^c NSW Civil and Administrative Tribunal, *NCAT Annual report 2019–2020*, p 45.

^d NSW Civil and Administrative Tribunal, *NCAT Annual report 2018–2019*, p 40.

^e NSW Civil and Administrative Tribunal, *NCAT Annual report 2017–2018*, p 44.

^f NSW Civil and Administrative Tribunal, *NCAT Annual report 2016–2017*, p 44.

Victoria

In Victoria, guardianship matters are dealt with by the Guardianship List, which sits within the Human Rights Division of the Victorian Civil and Administrative Tribunal (VCAT).

As at end of 2021–22, VCAT reported that over 17,000 Victorians were subject to a guardianship or administration order, or both.³ The total cases lodged with the guardianship list and applications for guardianship and administration orders in Victoria have varied between 2016–17 and 2021–22, as shown in Table 6A.3.

Table 6A.3: Overview of total cases lodged with the guardianship list and applications for guardianship and administration orders in Victoria between 2016 and 2022

Year	Total cases lodged with the guardianship list	Percentage change in lodgements for orders compared to the previous year ^a	Applications for guardianship and/or administration orders	Percentage change in lodgements for orders compared to the previous year
2021–2022	12,848	- 9% ^b	5,509	+ 1% ^c
2020–2021	14,169	+ 9% ^d	5,473	- 10% ^e
2019–2020	12,981	- 8% ^f	6,064	- 8% ^g
2018–2019	14,076	- 1% ^h	6,609	+ 10% ^h
2017–2018	14,249	+ 3% ⁱ	6,035	+ 10% ⁱ
2016–2017	13,896	+ 1% ^j	5,474	- 1% ^k

^a The percentage variance is the variance change from the prior year.

^b Victorian Civil and Administrative Tribunal, *2021–22 Annual report*, pp 34, 54.

^c Victorian Civil and Administrative Tribunal, *2021–22 Annual report*, p 54.

^d Victorian Civil and Administrative Tribunal, *Delivering justice in a time of change: Annual report 2020/21*, p 81.

^e VCAT attributes the decrease in the number of Guardianship and/or Administration applications (-10 per cent) to COVID-19. See Victorian Civil and Administrative Tribunal, *Delivering justice in a time of change: Annual report 2020/21*, pp 80–81.

^f VCAT attributes the decrease in the number of applications to COVID-19. The office experienced a reduction in staff which in turn caused delay in the listing of 1,359 initiations. VCAT reported that the actual initiation figure of 14,340 is similar to last year and that there has been an overall rise in the number of complex and urgent cases. See: Victorian Civil and Administrative Tribunal, *Annual report 2019–2020*, pp 17, 58–59.

^g Victorian Civil and Administrative Tribunal, *Annual report 2019–2020*, p 59.

^h Victorian Civil and Administrative Tribunal, *Annual report 2018–2019*, p 45.

ⁱ Victorian Civil and Administrative Tribunal, *Annual report 2017–2018*, p 46.

^j In financial year 2015–2016, the total number of lodgements with the guardianship list was 13,771. See Victorian Civil and Administrative Tribunal, *VCAT 2016–17 Annual report*, pp 6, 49.

^k In financial year 2015–2016, the total number of applications made in relation to guardianship and/or administration orders was 5,552. See Victorian Civil and Administrative Tribunal, *VCAT 2016–17 Annual report*, p 49.

Victoria is also in transition between its old *Guardianship and Administration Act 1986* (Vic) and the new *Guardianship and Administration Act 2019* (Vic). As at November 2022, of the 1,046 people who are subject to guardianship orders appointing the Victorian Public Advocate, 10 people are subject to guardianship orders made under the 1986 Act and 1,036 people are subject to guardianship orders made under the 2019 Act.⁴ Of the 9,252 people who are subject to administration orders appointing the State Trustees, 2,349 people are subject to administration orders made under the 1986 Act and 6,903 people are subject to administration orders made under the 2019 Act.⁵

The Victorian Office of the Public Advocate (OPA) has provided the Royal Commission with a 2023 report reflecting on guardianship law and practice in Victoria.⁶ As part of this report, Victorian OPA data was analysed over a 14-year period from 1 July 2008 to 30 June 2022 where the OPA was appointed guardian.

Table 6A.4 shows, across the 14 years from July 2008 to June 2022, the average time a represented person spent under OPA guardianship was 18 months.⁷ The OPA noted that grouping all represented persons together to calculate the average obscures the strong influence a person's age has on the length of time they spend under OPA guardianship. The average length of time represented persons under 65 years spent under OPA guardianship was 23 months during this period, compared with just 14 months for represented persons over 65 years.⁸ The OPA identified age as a reliable predictor of the length of time a person spends under OPA guardianship. The younger a person is at the time they are made subject to OPA guardianship, the longer they will typically spend under guardianship.⁹

Table 6A.4: Average time under OPA guardianship for represented persons whose (closed) matters were received between July 2008 and June 2022, by age when first order received

Age	Average number of months	Average number of months (excluding orders where people had died)
<20	29.3	29.4
20–34	28.4	28.5
35–40	24.7	25.4
50–64	22.6	23.1
65–79	15.2	15.8
80+	13.1	14.2
Grand total	18.2	19.3

Source: Office of the Public Advocate (Victoria), *Reflections on guardianship: The law and practice in Victoria*, Report, February 2023, p 50.

The 2019 Act also allows for the appointment of supported decision-makers. Under a Notice to Produce issued by the Royal Commission, VCAT advised, as at 3 November 2022, it had received 229 applications for supportive guardianship, of which it made 71 appointments of supportive guardians.¹⁰ Between 1 March 2020 and 3 November 2022, VCAT also received 189 applications for supportive administration. Of those, it made 99 appointments of supportive administrators.¹¹ These are illustrated in Table 6A.5.

Table 6A.5: Number of supportive orders under the *Guardianship and Administration Act 2019* (Vic) between 1 March 2020 and 3 November 2022

Outcome	Supportive guardianship order	Supportive administration order
Appointed	71	99
Adjourned	7	5
Dismissed	116	67
Revoked	2	0
Withdrawn	33	18
Total applications	229	189

Source: Exhibit 30-113, VIC.0015.0500.0901, pp 1–2.

Queensland

In Queensland, the Queensland Civil and Administrative Tribunal (QCAT) exercises its functions in relation to guardianship and administration in the Human Rights division.

For the year 2021–22, the QCAT received 11,594 applications for guardianship and administration orders.¹² QCAT made 961 orders appointing the Queensland Public Trustee as financial administrator and 2,034 orders appointing the Queensland Public Guardian as guardian.¹³ Table 6A.6 shows the number of applications for guardianship orders, including for restrictive practice matters, in Queensland between 2016 and 2022.

Table 6A.6: Overview of applications for guardianship and administration orders in Queensland between 2016 and 2022

Year	Lodged applications for guardianship orders	Percentage change in lodgements for orders compared to the previous year	Applications for guardianship for restrictive practice matters	Reviews of guardianship for restrictive practice matters
2021–2022	11,594	- 19.0% ^a	297	357 ^b
2020–2021	14,376	+ 5.0% ^c	240	302 ^d
2019–2020	13,724	+ 7.0% ^e	156	196 ^f
2018–2019	12,805	+ 1.0% ^g	104	315 ^h
2017–2018	12,684	+ 3.0% ⁱ	104	123 ^j
2016–2017	12,281	+ 6.0% ^k	78	363 ^l

^a QCAT attributes the decrease in the number of lodgements to the fact that the filing of annual accounts by appointed administrators are no longer counted as lodgements. The Tribunal notes that other areas of QCAT's guardianship jurisdiction have shown significant increases both in quantum and complexity. See Queensland Civil and Administrative Tribunal, *Annual report 2021–2022*, pp 14, 24.

^b Queensland Civil and Administrative Tribunal, *Annual report 2021–22*, p 40.

^c Queensland Civil and Administrative Tribunal, *Annual report 2020–21*, p 12.

^d Queensland Civil and Administrative Tribunal, *Annual report 2020–21*, p 33.

^e Queensland Civil and Administrative Tribunal, *Annual report 2019–20*, p 13.

^f Queensland Civil and Administrative Tribunal, *Annual report 2019–20*, p 34.

^g Queensland Civil and Administrative Tribunal, *Annual report 2018–19*, p 13.

^h Queensland Civil and Administrative Tribunal, *Annual report 2018–19*, p 35.

ⁱ Queensland Civil and Administrative Tribunal, *Annual report 2017–18*, p 14.

^j Queensland Civil and Administrative Tribunal, *Annual report 2017–18*, p 38.

^k Queensland Civil and Administrative Tribunal, *Annual report 2016–17*, p 15.

^l Queensland Civil and Administrative Tribunal, *Annual report 2016–17*, p 21.

Western Australia

In Western Australia, the State Administrative Tribunal (SAT) exercises its functions in relation to guardianship and administration in the Guardianship and Administration list within the Human Rights stream.¹⁴

For the year 2021–22, SAT received 5,602 applications for guardianship and administration matters, including 755 applications seeking the review of existing guardianship and administration orders, and 1,769 matters were mandatory statutory reviews of existing guardianship and administration orders.¹⁵ This was an increase of almost 11 per cent from the 2020–21 reporting period.¹⁶

Table 6A.7: Overview of applications for guardianship and administration orders in Western Australia between 2016 and 2022

Year	Applications relating to guardianship and administration	Percentage change in lodgements for orders compared to the previous year ^a
2021–2022 ^b	5,602	+ 10.7%
2020–2021 ^c	5,061	+ 3.2 %
2019–2020 ^d	4,903	+ 24.5%
2018–2019 ^e	3,938	+ 1.9%
2017–2018 ^f	3,864	- 0.4%
2016–2017 ^g	3,879	- 27.5% ^h

^a The percentage variance is the variance change in applications from the prior year.

^b State Administrative Tribunal, *Annual report 2021/22*, pp 16–17.

^c State Administrative Tribunal, *Annual report 2020/21*, pp 15–16.

^d State Administrative Tribunal, *Annual report 2019/20*, pp 13–14.

^e State Administrative Tribunal, *Annual report 2018/19*, p 11.

^f State Administrative Tribunal, *Annual report 2017/18*, p 11.

^g State Administrative Tribunal, *Annual report 2016/17*, p 11.

^h The SAT explains the sharp decrease in the number of applications is due to SAT's decision in March 2016 to treat applications for both guardianship and administration orders as a single application rather than two separate applications, as had been SAT's prior practice: State Administrative Tribunal, *Annual report 2016/17*, p 11.

South Australia

In South Australia, there is a Complex Guardianship and Administration list and a General Guardianship and Administration and Mental Health list within the South Australian Civil and Administrative Tribunal (SACAT).¹⁷ SACAT does not provide data on the orders for guardianship and administration in its annual reports.

For the year 2021–22, the South Australian Office of the Public Advocate (SA OPA) received 650 applications for initial guardianship orders in 2021–22. The SA OPA was appointed as guardian for 467 or 72 per cent of applications. This was a 7 per cent decrease in guardianship applications and a 13 per cent decrease in appointments of the Public Advocate from the previous year.¹⁸

Tasmania

In Tasmania, the Tasmanian Civil and Administrative Tribunal (TASCAT) was established in 2021 by the *Tasmania Civil and Administrative Tribunal Act 2020* (Tas).¹⁹ The Guardianship Stream is part of the Protective Division of TASCAT.²⁰ Prior to 2021, the Guardianship and Administration Board had authority to appoint guardians and administrators.

For the year 2021–22, TASCAT received 282 guardianship applications and 242 administration applications. Of the guardianship appointments made by TASCAT, 43 per cent were private guardians, 56 per cent were the Tasmanian Public Guardian, and 109 applications were dismissed or withdrawn. Of the administration appointments made, 58 per cent were private administrators, 42 per cent were the Public Trustee, and 44 applications were dismissed or withdrawn.²¹

Australian Capital Territory

In the Australian Capital Territory, guardianship and management of property matters are dealt with by the ACT Civil and Administrative Tribunal (ACAT).

For the year 2021–22, ACAT received 184 applications for guardianship and management of property orders.²²

Northern Territory

In the Northern Territory, the Northern Territory Civil and Administrative Tribunal (NTCAT) has adult guardianship jurisdiction.

For the year 2021–2022, NTCAT received 216 initial applications for guardianship²³ and made 171 new orders.²⁴

Profile of people under guardianship and administration orders

Types of impairment represented among people under orders

New South Wales

NCAT publishes data on types of impairment identified in applications for guardianship and financial management. As shown in Figure 6A.1, NCAT identified dementia as the most common (42 per cent) type of impairment of people subject to applications in the year 2021–22.²⁵

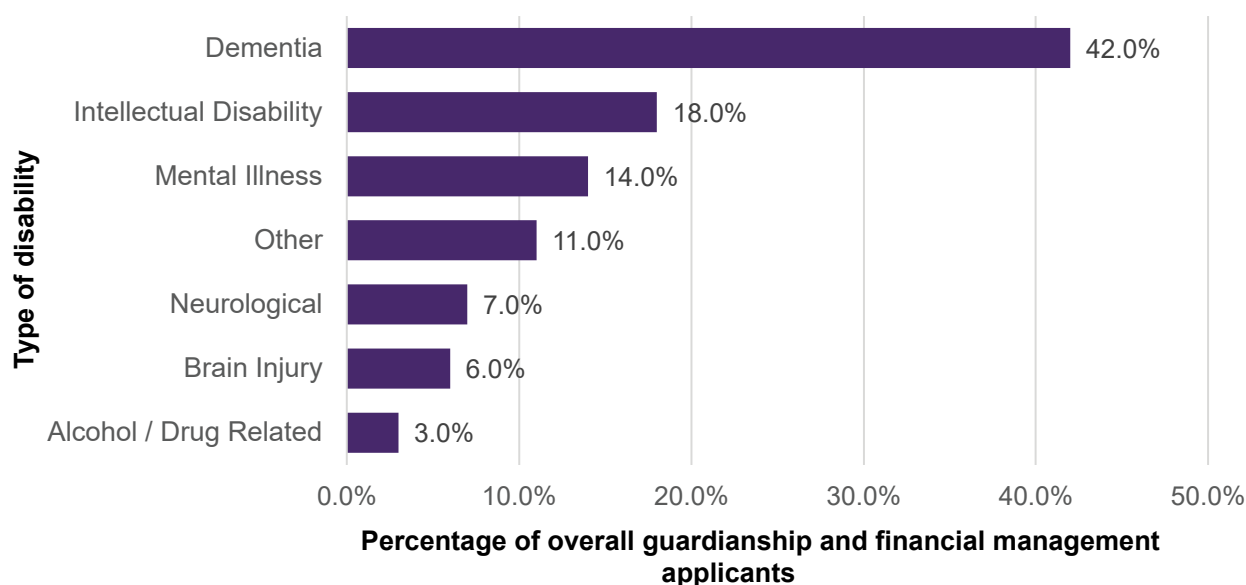


Figure 6A.1: Types of impairment identified in guardianship and financial management applications in 2021–22

Source: NSW Civil and Administrative Tribunal, *Annual report 2021–22*, p 42.

The NSW Trustee and Guardian also reports on the profile of people under orders appointing the Public Guardian or NSW Trustee and Guardian. Table 6A.8 shows that psychosocial and intellectual disability are the most common type of impairment represented among people appointed the Public Guardian or NSW Trustee and Guardian.

Table 6A.8: Types of impairment represented among people under orders appointing the New South Wales Public Guardian or NSW Trustee and Guardian as at 31 October 2022

Type of impairment	Public Guardian numbers ^a	Public Guardian percentages	NSW Trustee and Guardian numbers ^b	NSW Trustee and Guardian percentages
Psychiatric	962 ^c	25.8%	4,137	32.9%
Intellectual	1,298 ^d	34.8%	3,676	29.2%
Neurological	294 ^e	7.9%	411 ^f	3.3%
Dementia	632 ^g	17%	1,557 ^h	12.4%
Brain injury	232 ⁱ	6.2%	1,277	10.2%
Physical	12 ^j	0.3%	55	0.4%
Other	32 ^k	0.9%	1,292 ^l	10.3%

Note: Data only includes the primary disability types identified by the NSW Public Guardian and NSW Trustee and Guardian. People with multiple types of disability are included in 'Other'.

^a As at 31 October 2022. Exhibit 30-136, 'Statement of Megan Osborne', 14 November 2022, at [28]. The data is representative of the 'primary reason for incapacity for those represented' by the NSW Public Guardian. The NSW Public Guardian reported 264 (7.09 per cent) guardianship clients had no disability recorded'.

^b As at 31 October 2022. Exhibit 30-121, 'Statement of Caroline Cuddihy', 14 November 2022, at [36]. Note that there were 175 (1.39 per cent) of trustee clients with no disability recorded, and 920 (7.31 per cent) had multiple disability types.

^c This number includes anxiety, anorexia, bipolar, bulimia nervosa, depression, mental illness, personality disorders, schizophrenia, and trauma related disability.

^d This number includes intellectual disability, learning disorders, Asperger's, autism, autism spectrum disorder, cognitive disabilities, developmental disabilities and Down Syndrome.

^e This number includes Alzheimer's, cerebral palsy, developmental non-intellectual impairments, frontal temporal [sic], Huntington's disease, Lewy bodies, multiple sclerosis, muscular dystrophy, neurological, Parkinson's and stroke.

^f This number includes neurological and stroke.

^g This number includes advanced age, dementia, and dementia (alcohol related).

^h This number includes age related and HIV dementia.

ⁱ This number includes brain injury (acquired), brain injury (alcohol drug related), brain injury (other), brain injury (traumatic).

^j This number includes hearing impairments, and physical (other).

^k This number includes speech impairments, squalor, unknown, HIV/AIDS related, and vascular (multi-infarct).

^l This number includes categories described as 'multiple', 'other' and 'impairment substance abuse'.

Victoria

Table 6A.9 sets out the types of disability among people under guardianship and administration orders appointing the Public Advocate or State Trustees in Victoria.

Table 6A.9: Types of impairment represented among people under orders appointing the Public Advocate or State Trustees in Victoria as at October 2022

Type of impairment	Public Advocate numbers ^a	Public Advocate percentages	State Trustees numbers ^b	State Trustees percentages ^c
Psychiatric	467	44.6%	3,320 ^d	35.9%
Intellectual	482	46.1%	2,820 ^e	30.5%
Dementia	309	29.5%	1,418 ^f	15.3%
Brain injury	225	21.5%	1,188 ^g	12.8%
Physical	149	14.2%	185 ^h	2.0%

Note: Data only includes the primary disability types identified by the Victorian Public Advocate and State Trustees. Multiple disability types were recorded for 42 per cent (436 persons) of 1,036 represented persons appointed the Victorian Public Advocate.

^a As at 20 October 2022. Exhibit 30-099, 'Statement of Colleen Pearce', 5 November 2022, at [35], [43], table 3. The Victoria OPA had data recording at least one disability type for 1,036 represented persons. 436 of these represented persons had multiple disability types. We calculated the percentage of clients with each disability type with reference to the total number of people for whom the Public Advocate of Victoria acts as guardian (1,046), and not the number of people whom the Public Advocate of Victoria acts as guardian and has a recorded disability type (1,036 people).

^b As at 20 October 2022. Exhibit 30-081, 'Statement of John Velegrinis', 8 November 2022, at [4.7]. The data reflects disability types disclosed to the State Trustees and recorded on its data system. Mr Velegrinis records that 1,471 clients (16 per cent) did not have a disability type recorded. The total number of clients with a recorded disability type and no disability specified is 10,402 people. This suggests that clients may have multiple disability types recorded. We calculated the percentage of clients with each disability type with reference to the total number people for whom the State Trustees acts as administrator (9,252 people).

^c As at 20 October 2022. Exhibit 30-081, 'Statement of John Velegrinis', 8 November 2022, at [4.7]. The data reflects disability types disclosed to the State Trustees and recorded on its data system. Mr Velegrinis records that 1,471 clients (16 per cent) did not have a disability type recorded. The total number of clients with a recorded disability type and no disability specified is 10,402 people. This suggests that clients may have multiple disability types recorded. We calculated the percentage of clients with each disability type with reference to the total number people for whom the State Trustees acts as administrator (9,252 people).

^d This number includes schizophrenia, schizo-affective disorder, personality disorder, paranoid schizophrenia, depression, bipolar disorder and other mental illness.

^e This number includes Prader Willi syndrome and other intellectual impairment.

^f This number includes vascular dementia, Korsakoff's disease, Huntington's disease, dementia, cognitive impairment and Alzheimer's disease.

^g This number includes stroke, acquired brain injury (motor vehicle), ABI (drug related), ABI (alcohol related) and other ABIs.

^h This number includes Parkinson's disease, multiple sclerosis and other physical disabilities.

Queensland

Table 6A.10 sets out the types of impairment among people under guardianship and administration orders appointing the Public Guardian or Public Trustee.

Table 6A.10: Types of impairment represented among people under orders appointing the Public Guardian or Public Trustee in Queensland as at October 2022

Type of impairment	Public Guardian numbers ^a	Public Guardian percentages	Public Trustee numbers ^b	Public Trustee percentages
Psychosocial ^c	1,068	NA ^d	2,670 ^e	27.7%
Intellectual	1,506	NA	1,545 ^f	16.0%
Neurological	NA ^g	NA	1,112 ^h	11.5%
Dementia	446	NA	1,413 ⁱ	14.7%
Brain injury	535	NA	NA ^j	NA
Other	437 ^k	NA	953 ^l	9.9%

Note: 'NA' Indicates there is no publicly available data.

^a As at 27 October 2022. Exhibit 30-053, 'Statement of Shayna Smith', 11 November 2022, at [32]. The Public Guardian of Queensland notes that 'clients live with a range of disabilities, and many live with multiple disability.' The data reflects clients' 'primary disability'.

^b As at 27 October 2022. Exhibit 30-052, 'Statement of Samay Zhouand', 10 November 2022, at [24–25]. This data represents the 'primary disability' recorded by the Public Trustee of Queensland. The Public Trustee of Queensland reports that 1,942 (20.16 per cent) of its customers had no disability recorded.

^c This is categorised as 'psychiatric' in written statement provided by the Queensland Public Guardian for Public hearing 30.

^d We do not identify the percentage of clients with disability type here as the Public Guardian of Queensland's data shows that a 'primary disability' is recorded in 3,992 cases as at 27 October 2022, whereas it reports that as at 27 October 2022 it was appointed guardian for 3,565 adults.

^e This number includes schizoid disorder, anxiety disorder, mood disorder, personality disorder and addiction disorder.

^f The Public Trustee of Queensland uses the category of 'Developmental Disability'. The number includes intellectual disability, cerebral palsy, attention deficit/hyperactivity disorder (ADHD/ADD), down syndrome, foetal alcohol syndrome (FAS), Prada Willi syndrome, Phenylketonuria (PKU), Fragile X syndrome, Klinefelter syndrome and autism spectrum disorder (ASD).

^g The Public Guardian of Queensland does not categorise data of disability type by 'neurological' disability.

^h This number includes acquired brain injury, traumatic brain injury, cardiovascular accident/stroke, Parkinson's disease, Huntington's disease, motor neurone disease, multiple sclerosis, Wernicke Korsakoff's syndrome, muscular dystrophy, epilepsy and early onset dementia (<65 years).

ⁱ This number includes Alzheimer's and other dementia.

^j Brain injury is included under 'neurological disability'.

^k This includes disability types 'illness' and 'other'.

^l This number includes any other disability which is not a psychosocial disability, age related disability, neurological disability or developmental disability.

Western Australia

Table 6A.11 sets out the types of impairment among people under guardianship orders appointing the WA Public Advocate.

Table 6A.11: Types of impairment represented among people under guardianship and administration orders appointed the Public Advocate in Western Australia as at November 2022^a

Type of impairment	Number	Percentage
Psychosocial ^b	957	30.7%
Intellectual	884	28.4%
Dementia	779	25.0%
Brain injury	463	14.9%
Other	32 ²⁶	1.0%

^a As at 30 June 2022. The total people for whom the Public Advocate acted as guardian was 3,115 people.

^b This is categorised as 'mental illness' in a written statement provided by the Western Australian Public Advocate for Public hearing 30.

Source: Exhibit 30-008, 'Statement of Pauline Bagdonavicius', 4 November 2022, at [47].

South Australia

The SA OPA reported in its annual report for 2021–22 that intellectual disability (31 per cent) as the most common type of impairment of people represented, followed by mental illness (21 per cent), dementia (19 per cent), dual diagnosis (15 per cent), acquired brain injury (6 per cent) and other (8 per cent).²⁷

Tasmania

The Tasmanian Office of the Public Guardian reported that 51 per cent of represented persons had an intellectual disability (an increase from 45 per cent in 2020–21), 37 per cent had a psychiatric disability (up from 34 per cent in 2020–21), and 28 per cent had dementia (down from 34 per cent in 2020–21).²⁸

Australian Capital Territory

The Australian Capital Territory Public Trustee and Guardian publishes limited data on the profile of people under guardianship and financial management orders and does not publicly report on the type of impairment of people represented under orders.

Northern Territory

The Northern Territory Public Guardian and Trustee reported intellectual disability (229 persons) as the most frequently reported primary type of impairment for persons with Public Guardianship involvement, followed by dementia (166 persons) and acquired brain injury (137 persons).²⁹

Age of people under orders

New South Wales

In the 2021–22 reporting period, only NCAT reported on the age of people subject to applications for guardianship and financial management (administration) orders. As shown in Figure 6A.2, NCAT identified that people over the age of 75 account for the largest (42 per cent) age demographic of people subject of applications in 2021–22.³⁰

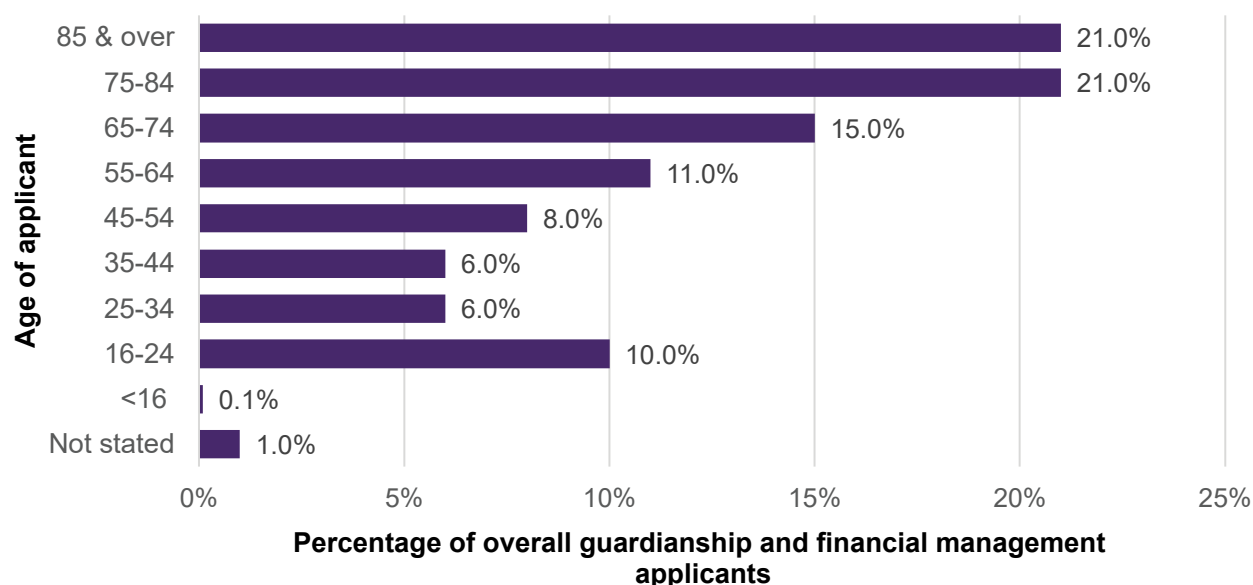


Figure 6A.2: Age demographic of the people subject of applications for guardianship and financial management in 2021–22

Source: NSW Civil and Administrative Tribunal, *Annual report 2021–22*, p 42.

The NSW Public Guardian and NSW Trustee and Guardian also provided data on the age profile of people appointed the Public Guardian or NSW Trustee and Guardian. Table 6A.12 shows that people 65 years and under were the largest age group of represented people.

Table 6A.12: Number and percentage of people under orders appointing the Public Guardian or Public Trustee in New South Wales by age group as at October 2022

Age group	Public Guardian numbers	Public Guardian percentages	Public Trustee numbers	Public Trustee percentages
65 and under	2,421	65.0% ^a	8,477	67.4% ^b
66 and over	1,305	35.0% ^a	4,096	32.6% ^b

^a As at 31 October 2022.

^b As at 31 October 2022. Seven clients (0.06 per cent) do not have an age recorded.

Source: Exhibit 30-136, 'Statement of Megan Osborne', 14 November 2022, at [29]; Exhibit 30-121, 'Statement of Caroline Cuddihy', 14 November 2022, at [37].

Victoria

Tables 6A.13 and 6A.14 sets out the number and percentage of people under orders appointing the Victorian Public Advocate or State Trustees by age group.

Table 6A.13: Number and percentage of people under orders appointing the Victorian Public Advocate by age group as at October 2022^a

Age group	Number of people represented	Percentage of people represented
64 and under	696	66.5%
65 and over	350	33.5%

^a As at 20 October 2022.

Source: Exhibit 30-099, 'Statement of Colleen Pearce', 5 November 2022, at [44].

Table 6A.14: Number and percentage of people under orders appointing the State Trustees in Victoria by age group as at October 2022^a

Age group	Number of people represented	Percentage of people represented
59 and under	5,106	55.2%
60 and over	4,149	44.8%

^a As at 20 October 2022. One client is of an unknown age.

Source: Exhibit 30-081, 'Statement of John Velegrinis', 8 November 2022, at [4.7](i).

The 2023 Victorian OPA report identified a sustained upward trend in the numbers of people under 65 years old who are under OPA guardianship since 2008. This is compounded by the greater lengths of time this group spends subject to orders.³¹

The OPA observed that it has seen a large increase in the demand for guardianship services for people under 65 years. The upward trend for cohorts under 65 years became more pronounced after 2015–16. The OPA further observed a notable decline in total demand for OPA guardianship for people over 65 years since 2017–18.³²

Table 6A.15 demonstrates an upward trend in the average length of time people under 65 years spent under OPA guardianship across the last 10 years.³³

Table 6A.15: Average length of time (in months) under Victorian OPA guardianship for represented persons with matters received in the nominated year, by age cohort, between 2011 and 2020

Year	People over 65 years old	People under 65 years old	All represented persons
2019–20	17.8	30.3	24.5
2015–16	18.4	24.8	21.4
2014–15	17.4	26.9	21.3
2010–11	16.0	24.0	19.2

Note: To explore whether average time under OPA guardianship has varied over time, the data was divided into five-year blocks of time. Averages were calculated using data from all the people for whom OPA received an order during the middle year of the relevant period. These averages will be underestimates, as they do not consider orders for the year-cohort that were received prior to or following the nominated five-year period. However, this approach is necessary to enable comparison over time.

Source: Exhibit 30-099, 'Statement of Colleen Pearce', 5 November 2022, at [42].

The OPA also explored the impact that the person's disability profile had on average time under OPA guardianship. The relationship between age and length held, irrespective of a person's disability, except where the numbers of people in each age group were insufficient to be representative.³⁴

Queensland

Tables 6A.16 and 6A.17 sets out the number and percentage of people under orders appointing the Public Guardian and Public Trustee by age group.

Table 6A.16: Number and percentage of people under orders appointing the Queensland Public Guardian by age group as at November 2022^a

Age group	Number of people represented	Percentage of people represented
64 and under	2,675	75.1%
65 and over	888	24.9%

^a As at 27 October 2022.

Source: Exhibit 30-053, 'Statement of Shayna Smith', 11 November 2022, at [33].

Table 6A.17: Number and percentage of people under orders appointing the Queensland Public Trustee by age group as at November 2022^a

Age group	Number of people represented	Percentage of people represented
59 and under	5,491	57.0%
60 and over	4,144	43.0%

^a As at 27 October 2022.

Source: Exhibit 30-052, 'Statement of Samay Zhouand', 10 November 2022, at [27].

Western Australia

Table 6A.18 sets out the number and percentage of people under orders appointing the WA Public Advocate by age group.

Table 6A.18: Number and percentage of people under orders appointing the Western Australia Public Advocate by age group as at November 2022

Age group	Number of people represented	Percentage of people represented
65 and under	1,973	63.3% ^a
66 and over	1,142	36.7% ^a

^a As at 30 June 2022.

Source: Exhibit 30-008, 'Statement of Pauline Bagdonovicius', 4 November 2022, at [48].

South Australia

For the 2021–22 reporting period, the SA OPA reported approximately a third (34 per cent) of represented persons are between 40 and 64 years and slightly more than a third (37 per cent) are over the age of 65 years.³⁵

Tasmania

In the 2021–22 reporting period, the Tasmania Office of the Public Guardian reported an increase in the 36–60 years age bracket, and a decrease in the number of represented people aged 61–80 years, compared with 2020–21.³⁶

Australian Capital Territory

The Australian Capital Territory Public Trustee and Guardian publishes limited data on the profile of people under guardianship and financial management orders and does not publicly report on the age of people represented under orders.

Northern Territory

For the year 2021–22, the Public Guardian and Trustee reported a third of represented persons with Public Guardian involvement are aged 65 and above. The 65 years and over age group of persons with Public Guardian involvement (221 persons) represents around 1 per cent of the total estimated resident population aged 65 and over in the Northern Territory.³⁷

First Nations and cultural representation

New South Wales

In New South Wales, the NSW Trustee reported that, as at November 2022, 7 per cent of its clients identified as First Nations.³⁸ The NSW Public Guardian reported that 9 per cent of people under guardianship identified as First Nations.³⁹ The general population of First Nations people in New South Wales was approximately 4 per cent.⁴⁰

Victoria

In Victoria, 4 per cent of the 1,046 people under guardianship⁴¹ and 1 per cent of the 9,252 people under administration⁴² identify as First Nations people. At Public hearing 30, Dr Colleen Pearce spoke of an overrepresentation of First Nations people under guardianship despite the potential for underreporting given that identification as First Nations is optional.⁴³

Queensland

Both the Queensland Public Trustee and the Queensland Public Guardian have identified a disproportionate number of First Nations people under guardianship and administration in Queensland.⁴⁴ In the year 2021–22, the Queensland Public Trustee told us 9 per cent of the 9,635 people it represented identified as First Nations people.⁴⁵ For the same period, the Public Guardian reported that 16 per cent of the 3,565 people under its guardianship identified as First Nations people.⁴⁶

Western Australia

As at 30 June 2022, the WA Public Advocate was guardian for 570 First Nations people. This represents 17 per cent of 3,115 appointments of the Public Advocate. At Public hearing 30, the Public Advocate acknowledged this was a significant overrepresentation, compared with the overall population of First Nations people in the state of 4.2 per cent.⁴⁷

South Australia

In the 2021–22 reporting period, the SA OPA reported that First Nations people represented under guardianship accounted for 11 per cent of all represented persons, which is 1 per cent higher than the previous year. The SA OPA noted that First Nations people under guardianship are overrepresented compared with their proportion of the South Australian population (2 per cent).⁴⁸

Tasmania

Between 2017 and 28 October 2022, the Tasmanian Public Guardian was appointed for six First Nations people.⁴⁹

Australian Capital Territory

For the year 2021–22, the Public Trustee and Guardian reported that 15 First Nations people received guardianship services and 10 First Nations people received financial management services.⁵⁰

Northern Territory

In the 2021–22 reporting period, the Public Guardian and Trustee reported that most people involved with guardianship in the Northern Territory identify as First Nations (56 per cent). The majority of represented persons who identify as First Nations have Public Guardian involvement (76 per cent). Most represented persons who identify as non-Indigenous have private guardians solely appointed (71 per cent).⁵¹

Appendix 6B – Guidelines for Australian Tribunals – Maximising the participation of the person in guardianship proceedings⁵²

GUIDELINE 1: Promptly, but no later than 10 days from the date the application was lodged, the Tribunal should give, or require the applicant to give, a copy of the application and any supporting documents to the Person and the other parties. Where the applicant is required to give to the Person and the other parties, a copy of the application and any supporting documents, the Tribunal should require the applicant to provide evidence that this occurred. The Tribunal will determine how this evidence should be provided.

GUIDELINE 2: The Tribunal should give to the Person and the other parties, written notice of the hearing no later than 7 working days before the hearing except in special circumstances, such as where there are reasonable grounds to conclude that the Person will be at risk if determining the application is delayed. Registry staff should consider whether any additional steps need to be taken to ensure that the Person is informed of the details of the hearing, unless otherwise ordered by the Tribunal.

GUIDELINE 3: Pre-hearing processes should ensure that:

- the Person is made aware of the application
- information is provided to assist the Person to understand what the application and hearing are about
- the Person's participation is encouraged and facilitated
- any further information that may assist the Tribunal is obtained from the Person
- the Person is provided with information about representation including advocacy (if any)
- information is given to the Person about Tribunal practice and procedure and to assist in addressing any confusion or anxiety
- the Person has an opportunity to ask questions about any of these matters
- information is sought as to whether any communication supports are required by the Person, for example, interpreting services, visual, auditory or communication aids.

GUIDELINE 4: The listing of a hearing should take into account:

- whether the Person requires a hearing at certain times of the day (for example, a morning rather than afternoon hearing to accommodate the likely effects of medication on the Person)

- an estimate of how long the Person needs to give their views to the Tribunal, having regard to their communication needs
- any need for breaks during the hearing
- any additional time likely to be required for the use of an interpreter.

GUIDELINE 5: Information about various aspects of the Tribunal's practice and procedure (both in hard copy and online) should be made available to the Person in formats that are accessible to people:

- from culturally and linguistically diverse backgrounds
- with a vision and/or hearing impairment
- with cognitive disabilities.

GUIDELINE 6: Where practicable, hearings should be listed in a location that allows the Person to participate in the hearing in-person.

GUIDELINE 7: If a face-to-face hearing is not possible, then other means to enable the Person to participate in the hearing should be explored. This may include:

- measures similar to those undertaken by the South Australian Civil and Administrative Tribunal involving a "Visit to the Person" by a Tribunal member
- the views of the Person being provided by way of a representative
- video-conferencing
- telephone participation.

GUIDELINE 8: Tribunals should collect data and report publicly on:

- the participation rates of Persons in hearings, broken down into in-person participation, hearings by videoconference and hearings by telephone
- the rate of appointment of representatives, broken down into the appointment of public representatives and private representatives
- the number of appointments of representatives that are revoked, varied, or reviewed.

GUIDELINE 9: Tribunals should collect data and report publicly on the rate of appointment of legal representatives, separate representatives and guardians ad litem to represent the Person in proceedings.

GUIDELINE 10: Hearing venues should:

- be wheelchair accessible
- have drop-off zones for people with mobility restrictions

- have easily accessible parking
- be accessible by public transport
- provide accessible toilets.

GUIDELINE 11: Tribunals should consider the amenity of waiting room spaces, given the impact this can have on the Person's anxiety levels leading up to the hearing and their ability to participate in the hearing.

GUIDELINE 12: Tribunals should consider the amenity and configuration of hearing rooms. Hearing rooms should:

- provide the option of a more informal setting than a traditional courtroom; for example, a meeting table, no elevated bench for Tribunal members, and flexible seating arrangements to assist in putting the Person at ease
- provide hearing induction loop facilities
- provide video conference and teleconference facilities.

GUIDELINE 13: The Person may be accompanied by a support person during the hearing unless the Tribunal determines that the proposed support person is acting, or is likely to act, in a manner contrary to the Person's interests. A support person could be a family member, close friend, disability advocate, or other person who is able to provide assistance and support.

GUIDELINE 14: In those jurisdictions that require the leave of the Tribunal for a party to be legally represented at the hearing, any application made by or on behalf of the Person who is the subject of the application should be determined at the earliest possible opportunity. This ensures that the Person and their legal representative have adequate time to prepare.

GUIDELINE 15: In those jurisdictions that provide for the appointment of a separate representative or guardian ad litem for the Person, consideration of whether such an appointment should be made should occur at the earliest opportunity.

GUIDELINE 16: Tribunal members need to be trained in the use of communication supports that a Person may require to participate in the hearing including interpreting services, visual and auditory aids and other communication aids including different forms of augmentative and alternative communication tools.

GUIDELINE 17: Given the centrality of the Person who is the subject of guardianship and/or administration proceedings, the Person should have a genuine opportunity to participate in an oral hearing before a determination is made.

GUIDELINE 18: Original applications should be determined after an oral hearing.

GUIDELINE 19: Reviews of existing orders should ordinarily be determined after an oral hearing. Where reviews of orders are determined without an oral hearing, before making a determination the Tribunal should make reasonable attempts to obtain the views of the Person, up-to-date medical information about whether the Person continues to have a decision-making disability and the Person's current circumstances.

GUIDELINE 20: Acknowledging that some jurisdictions are constrained by their enabling legalisation [sic] regarding composition of panels, consideration should be given to using multi-member panels to ensure that the Tribunal has the breadth of skills and experience relevant to the circumstances of the Person and the issues to be determined in the particular matter.

GUIDELINE 21: Multi-disciplinary panels, constituted by members with relevant and different areas of expertise, are optimal in appropriate circumstances.

GUIDELINE 22: Given, however, the practical constraints that exist for each of the jurisdictions, multi-disciplinary panels should at least be used in matters assessed as being complex, or that would otherwise benefit from particular professional expertise or community-based experience.

GUIDELINE 23: Tribunals should have available to them members from a diversity of backgrounds with particular expertise in relation to communicating with people with disabilities.

GUIDELINE 24: Training for members and registry staff about strategies to involve the Person in guardianship proceedings is critical. Such training would allow members and registry staff to be better informed about the communication needs of persons with particular disabilities and the characteristics associated with different disabilities.

GUIDELINE 25: Tribunals should seek to increase their staffing and membership of Aboriginal and Torres Strait Islander people as well as non-Indigenous members and staff with an understanding of the culture, values and beliefs held by Aboriginal and Torres Strait Islander people.

GUIDELINE 26: Members and registry staff should be given training which promotes awareness of cultural considerations relevant to Aboriginal and Torres Strait Islander people and culturally and linguistically diverse people.

Endnotes

- 1 NSW Civil and Administrative Tribunal, *Annual report 2021–22*, p 43.
- 2 Submissions by the NSW Civil and Administrative Tribunal in response to Counsel Assisting's submissions in Public hearing 30, 22 February 2023, SUBM.0021.0004.0001, p 2 [12]. Note: Due to rounding two shares mentioned exceed 100 per cent. See also: NSW Civil and Administrative Tribunal, *NCAT Annual report 2021–2022*, p 43.
- 3 Victorian Civil and Administrative Tribunal, *Annual report 2021–22*, p 52.
- 4 As at 20 October 2022 Exhibit 30-099, 'Statement of Colleen Pearce', 5 November 2022, at [35], [39–40].
- 5 Exhibit 30-081, 'Statement of John Velegrinis', 8 November 2022, at [4.3–4.5].
- 6 Office of the Public Advocate (Vic), *Reflections on guardianship: The law and practice in Victoria*, Report, February 2023.
- 7 Office of the Public Advocate (Vic), *Reflections on guardianship: The law and practice in Victoria*, Report, February 2023, p 48.
- 8 These calculations include all closed matters for all represented persons with matters received between July 2008 and June 2022 (and does not exclude people whose matters were closed due to death): Office of the Public Advocate (Vic), Response to questions from the Royal Commission, 8 March 2023, OPA.9999.0013.0001, p 50.
- 9 Office of the Public Advocate (Vic), *Reflections on guardianship: The law and practice in Victoria*, Report, February 2023, p 48.
- 10 Exhibit 30-113, VIC.0015.0500.0901, pp 1–2.
- 11 Exhibit 30-113, VIC.0015.0500.0901, pp 1–2.
- 12 Queensland Civil and Administrative Tribunal, *Annual report 2021–22*, p 12.
- 13 Exhibit 30-052, 'Statement of Samay Zhouand', 10 November 2022, at [41]; Exhibit 30-053, 'Statement of Shayna Smith', 11 November 2022, at [38].
- 14 State Administrative Tribunal, *Annual report 2021–22*, p 16.
- 15 State Administrative Tribunal, *Annual report 2021–22*, p 16.
- 16 State Administrative Tribunal, *Annual report 2021–22*, p 16.
- 17 South Australian Civil and Administrative Tribunal, *Annual report 21–22*, p 6.
- 18 Office of the Public Advocate (SA), *Annual report 2021–22*, pp 14–15.
- 19 *Tasmania Civil and Administrative Tribunal Act 2020* (Tas) s 8.
- 20 Tasmanian Civil and Administrative Tribunal, *Annual report 2021–22*, October 2022, p 14.
- 21 Tasmanian Civil and Administrative Tribunal, *Annual report 2021–22*, October 2022, p 30.
- 22 Australian Capital Territory Civil and Administrative Tribunal, *Annual report 2021–22*, p 41.
- 23 Northern Territory Civil and Administrative Tribunal, *Annual report 2021–22*, p 19.
- 24 Northern Territory Civil and Administrative Tribunal, *Annual report 2021–22*, p 21.
- 25 NSW Civil and Administrative Tribunal, *Annual report 2021–22*, p 42 (Graph 6).
- 26 Exhibit 30-008, 'Statement of Pauline Bagdonavicius', 4 November 2022, at [47]. Note that 30 of the 32 'other' are for represented persons with Autism Spectrum Disorder.
- 27 Office of the Public Advocate (SA), *Annual report 2021–22*, p 12.
- 28 Office of the Public Guardian (Tas), *Annual report 2021–22*, p 16.
- 29 Northern Territory Public Guardian and Trustee, *Annual report 2021–22*, p 35.
- 30 NSW Civil and Administrative Tribunal, *Annual report 2021–22*, p 42 (Graph 5).
- 31 Office of the Public Advocate (Vic), *Reflections on guardianship: The law and practice in Victoria*, Report, February 2023, p 48.
- 32 Office of the Public Advocate (Vic), *Reflections on guardianship: The law and practice in Victoria*, Report, February 2023, p 53.
- 33 Office of the Public Advocate (Vic), *Reflections on guardianship: The law and practice in Victoria*, Report, February 2023, p 51.
- 34 Office of the Public Advocate (Vic), *Reflections on guardianship: The law and practice in Victoria*, Report, February 2023, p 51.
- 35 Office of the Public Advocate (SA), *Annual report 2021–22*, pp 10–11.
- 36 Office of the Public Guardian (Tas), *Annual report 2021–22*, p 15.
- 37 Northern Territory Public Guardian and Trustee, *Annual report 2021–22*, p 34 (Figure 14).
- 38 Exhibit 30-121, 'Statement of Caroline Cuddihy', 14 November 2022, at [39].

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- 39 Exhibit 30-136, 'Statement of Megan Osborne', 14 November 2022, at [31].
- 40 Australian Institute of Health and Welfare, 'Profile of Indigenous Australians', *Australian Institute of Health and Welfare*, web article, 7 July 2022. <<https://www.aihw.gov.au/reports/australias-health/profile-of-indigenous-australians>>
- 41 Exhibit 30-099, 'Statement of Colleen Pearce', 5 November 2022, at [38], [46]; Exhibit 30-211, OPA.9999.0012.0001, p 2.
- 42 Exhibit 30-081, 'Statement of John Velegrinis, CEO of State Trustees', 8 November 2022, at [4.3], [4.8].
- 43 Transcript, Colleen Pearce, Public hearing 30, 23 November 2022, P-336 [9]; Exhibit 30-099, 'Statement of Colleen Pearce', 5 November 2022, at [46].
- 44 Transcript, Samay Zhouand and Shayna Smith, Public hearing 30, 22 November 2022, P-203 [14], [38–39].
- 45 Exhibit 30-052, 'Statement of Samay Zhouand', 10 November 2022, at [21], [30].
- 46 Exhibit 30-053, 'Statement of Shayna Smith', 11 November 2022, at [27], [35].
- 47 Exhibit 30-008, 'Statement of Pauline Bagdonavicius', 4 November 2022, at [50]; Transcript, Pauline Bagdonavicius, Public hearing 30, 21 November 2022, P-77 [33–35]. See also: Australian Institute of Health and Welfare, 'Profile of Indigenous Australians', *Australian Institute of Health and Welfare*, web article, 7 July 2022. <<https://www.aihw.gov.au/reports/australias-health/profile-of-indigenous-australians>>
- 48 Office of the Public Advocate (SA), *Annual report 2021–22*, p 10.
- 49 As at 28 October 2022, Exhibit 30-201, 'Statement of Angela McCrossen' 8 November 2022, p 5.
- 50 ACT Public Trustee and Guardian, *Annual report 2021–22*, p 44.
- 51 Northern Territory Public Guardian and Trustee, *Annual report 2021–22*, p 35.
- 52 Australian Guardianship and Administration Council, *Guidelines for Australian Tribunals*, Final report, June 2019.

Acronyms and abbreviations

ACAT – Australian Capital Territory Civil and Administrative Tribunal

ACEM – Australasian College of Emergency Medicine

ACQSC – Aged Care Quality and Safety Commission

ACRRM – Australian College of Rural and Remote Medicine

ACSQHC – Australian Commission on Safety and Quality in Health Care

ACTLRAC – ACT Law Reform Advisory Council

ADE – Australian Disability Enterprise

ADS – Australia’s Disability Strategy 2021–2031

AGAC – Australian Guardianship and Administration Council

Aged Care Royal Commission – Royal Commission into Aged Care Quality and Safety

AHRC – Australian Human Rights Commission

AIHW – Australian Institute of Health and Welfare

ALRC – Australian Law Reform Commission

ALRC report – Australian Law Reform Commission, *Equality, capacity and disability in Commonwealth laws*

AMC – Australian Medical Council

ANZCA – Australian and New Zealand College of Anaesthetists

APO – Authorised Program Officer (SA)

Authorisations Act – National Disability Insurance Scheme (Authorisations) Act 2019 (NT)

CEO – Chief Executive Officer

COAG – Council of Australian Governments

CPD – Continuing Professional Development

CRPD – Convention on the Rights of Persons with Disabilities

CRPD Committee – United Nations Committee on the Rights of Persons with Disabilities

DANA – Disability Advocacy Network Australia

DDA – *Disability Discrimination Act 1982* (Cth)

Disability Inclusion Regulations – Disability Inclusion (Restrictive Practices—NDIS) Regulations 2021 (SA)

Draft Principles for Consistent Authorisation – Draft Principles for Nationally Consistent Authorisation of Restrictive Practices

DSOA – Disability Support for Older Australians Program

FIP – Financial Independence Program

Joint statement – Joint statement on the inappropriate use of psychotropic medicines to manage the behaviours of people with disability and older people

LGBTIQ+ – Lesbian, gay, bisexual, transgender, intersex, queer or questioning, and asexual

Marion's case – Secretary of the Department of Health and Community Services v JWB & SMB (1992) 175 CLR 218

MDANZ – Medical Deans Australia and New Zealand

NAATI – National Accreditation Authority for Translators and Interpreters

National Framework – National Framework for Reducing and Eliminating the Use of Restrictive Practices in the Disability Services Sector

National Roadmap – National Roadmap for Improving the Health of People with Intellectual Disability

NCAT – New South Wales Civil and Administrative Tribunal

NDAF – National Disability Advocacy Framework

NDAP – National Disability Advocacy Program

NDIA – National Disability Insurance Agency

NDIS – National Disability Insurance Scheme

NDIS Act – National Disability Insurance Scheme Act 2013 (Cth)

NDIS Commission – NDIS Quality and Safeguards Commission

NDIS Commissioner – NDIS Quality and Safeguards Commissioner

NDIS Framework – National Disability Insurance Scheme Quality and Safeguarding Framework

NDIS Restrictive Practices Rules – National Disability Insurance Scheme (Restrictive Practices and Behaviour Support) Rules 2018 (Cth)

NEDA – National Ethnic Disability Alliance

No Force First – No Force First Project

Northern Territory Royal Commission – Royal Commission into the Protection and Detention of Children in the Northern Territory

NSWLRC – New South Wales Law Reform Commission

NSW Policy – Restrictive Practices Authorisation Policy (NSW)

NSW Policy Directive – Seclusion and Restraint in NSW Health Settings Policy Directive

NSW Trustee – NSW Trustee and Guardian

NTCAT – Northern Territory Civil and Administrative Tribunal

OPA – Office of the Public Advocate

Pathway to elimination report – University of Melbourne, University of Technology Sydney and University of Sydney, *Restrictive practices: A pathway to elimination*, Report prepared for the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, 25 July 2023

PRN – *pro re nata* or ‘as needed’

Psychotropic Medicines Standard – Psychotropic Medicines in Managing Changed Behaviours Clinical Care Standard

QCAT – Queensland Civil and Administrative Tribunal

RACP – Royal Australasian College of Physicians

Reducing restrictive practices report – Social Policy Research Centre, University of New South Wales, *Reducing restrictive practices: A review of evidence-based alternatives*, Report prepared

for the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, 8 August 2023

Restrictive Practices Policy – Authorisation of Restrictive Practices in Funded Disability Services Policy (WA)

RPA Panel – Restrictive Practices Authorisation Panel (NSW)

SA Policy Directive – Minimising Restrictive Practices in Health Care Policy Directive

SA Protective Practices Guidelines – Protective practices for staff in their interactions with children and young people: Guidelines for staff working or volunteering in education or care settings

SAO – Senior Authorising Officer (SA)

Six Core Strategies – Six Core Strategies to Reduce Seclusion and Restraint Use

SPECTROM – Short-Term Psycho-Education for Caregivers to Reduce Overmedication of People with Intellectual Disabilities program developed in the United Kingdom

Standing Order 10A – Chief Civil Psychiatrist’s Mechanical and Physical Restraint Chief Civil Psychiatrist Standing Order 10A (Tas)

TASCAT – Tasmanian Civil and Administrative Tribunal

TIS – Translating and Interpreting Service

TLRI – Tasmanian Law Reform Institute

UK Standard – Accessible Information Standard

VALiD – Victorian Advocacy League for Individuals with Disability

VCAT – Victorian Civil and Administrative Review Tribunal

Victorian Royal Commission – Royal Commission into Victoria’s Mental Health System

VLRC – Victorian Law Reform Commission

WWILD – WWILD Sexual Violence Prevention Association Inc



Royal Commission
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Exploitation of People with Disability