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

Beyond the Royal Commission

Final Report
Volume 12

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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.

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Summary

Key points

- This last volume of the *Final report* recommends key steps for implementing and monitoring the recommendations of the Royal Commission:
    - The Australian Government and state and territory governments should each publish a written response to the *Final report* by 31 March 2024.
    - The Disability Reform Ministerial Council should oversee the implementation of our recommendations.
    - The independent National Disability Commission should provide an annual assessment on the implementation of our recommendations.
    - The National Disability Commission should evaluate the effectiveness of our recommendations five and 10 years after delivery of this report.
- High quality data and research are important for measuring the effectiveness of policy and holding governments and organisations to account. We recommend ways to improve the evidence base for disability policy and services.
- Data about people with disability is dispersed across various datasets, using at least nine different definitions of ‘disability’. The Disability Reform Ministerial Council should develop a nationally consistent approach to collecting disability information and support the wider adoption of a disability flag in data collections to identify people with disability. This will help to ensure the experiences of people with disability are better understood.
- Strategies should be developed to improve data collection about people with disability in closed and segregated settings, those with communication support needs, and groups with intersecting and multiple disadvantage. (See the section ‘A note on language’.)
- The Disability Reform Ministerial Council should establish the National Disability Data Asset as a national resource for linked, longitudinal analysis.
- A royal commission can prompt significant changes to legislation, policies and attitudes. We identify the key impacts this Royal Commission has had during our inquiry. We acknowledge our work is built on the long-term advocacy of people with disability and their supporters to improve the lives of people with disability.

In this *Final report*, we make a range of recommendations designed to achieve significant change for people with disability. If implemented, they will help prevent violence against, and abuse, neglect and exploitation of, people with disability. These changes will also embed the human rights of people with disability in government policy and practices to ensure respect for their inherent dignity and individual autonomy.

In this last volume, we discuss:

- the implementation of our recommendations
- the need to improve data and research to build the evidence base for disability policy and services
- the impact of this Royal Commission during our inquiry.

The volume has three chapters.

Chapter 1, 'Delivering change'

Chapter 1, 'Delivering change', recommends four steps for implementing and monitoring our recommendations.

First, the Australian Government and state and territory governments should each publish a written response to the *Final report* by 31 March 2024.

People with disability, their supporters and representative organisations have been at the centre of our work and have invested a great deal in the Royal Commission. They rightly expect governments to respond in a timely manner to our recommendations.

Second, the Disability Reform Ministerial Council should oversee the implementation of our recommendations.

Improving outcomes for people with disability requires action at all levels of government, in the private sector and in the community. Governments will need to collaborate with each other and particularly with disability organisations and people with disability to implement our recommendations. The Disability Reform Ministerial Council should be a single coordination point and provide a forum for government to address implementation issues and risks.

Third, the new independent National Disability Commission should assess the progress of the implementation of our recommendations across each jurisdiction. Starting in 2025, it should deliver an annual report of its findings to the Australian Parliament. The views of people with disability on whether recommendations are being implemented effectively will be critical to evaluating progress.

The fourth step will be understanding whether implementation of our recommendations has led to significant and measurable change for people with disability over time. We recommend the National Disability Commission should evaluate and report on the effectiveness of the recommendations five and 10 years after delivery of this report.

Chapter 2, ‘Building the policy evidence’

Chapter 2, ‘Building the policy evidence’, begins by noting that the Royal Commission had difficulty during the inquiry obtaining reliable and useful data and research. This hindered our understanding of violence against, and abuse, neglect and exploitation of, people with disability, and how to address and prevent it.

The chapter identifies four important ways to improve the collection and analysis of data about the experiences of people with disability.

First, we consider how data on disability can be improved by developing a nationally consistent approach to collecting disability information.

Second, we recommend wider adoption of a disability flag across data collections for mainstream services to identify people with disability. ‘Flags’ help to identify particular groups of interest, such as people with disability, in data collections. They can be formed by how people answer a set of questions when accessing services.

These initiatives will support the collection of more informative data about people with disability. They will also help provide a stronger evidence base for informing policy development, monitoring outcomes and better understanding the experiences of people with disability in Australia.

Third, we recommend extending the collection of disability data:

- to include groups of people with disability who are particularly at risk of violence, abuse, neglect and exploitation. This includes people in closed and segregated settings and those with communication support needs (see the section ‘A note on language’)
- to improve data on type of impairment
- to improve data for intersectional analysis by enhancing data on women with disability; children and young people with disability; and First Nations, culturally and linguistically diverse, and LGBTIQA+ people with disability.

Fourth, we propose establishing the National Disability Data Asset (NDDA) as a national resource for linked data across service systems. Data linkage helps create a comprehensive picture of the experiences of people with disability. It also enables longitudinal analysis to help understand trends and provides an evidence base for inclusive service and system design. The NDDA will help shift away from disconnected data, organised around government agencies and services, to give a more complete picture of the lives of people with disability.

The chapter also looks at the current state of disability research in Australia and our research agenda. We acknowledge the Australian Government’s National Disability Research Partnership (NDRP), an initiative facilitating a more collaborative approach to disability research.

Chapter 3, ‘Our impact’

Chapter 3, ‘Our impact’, identifies the key impacts the Royal Commission has had on policy, programs and services during our inquiry.

Our reports and public hearings influenced the policy environment, and in some cases triggered initiatives to strengthen government policies and programs.

The chapter begins with the Royal Commission’s impact on the Australian Government’s response to the COVID-19 pandemic for people with disability. It then identifies other significant results, including:

- changes to education policies on suspensions of students with disability
- reviews of the performance of Disability Employment Services (DES) providers
- initiatives to improve the health care of people with cognitive disability
- measures to tackle violence against women and girls with disability.

We recognise our work was not conducted in isolation. It built on long-term advocacy by people with disability and their supporters to improve the lives of people with disability.

A note on language

As Volume 7, *Inclusive education, employment and housing* shows, Commissioners have different views as to the meaning and significance of the terms ‘segregation’ and ‘segregated settings’.

Commissioners Bennett, Galbally and McEwin consider all group homes, Australian Disability Enterprises, day programs and special schools, as well as prisons, detention centres and similar institutions are ‘closed and segregated’ settings.

The Chair and Commissioners Mason and Ryan do not share this view. Their position as explained in Volume 7, is that whether these settings should properly be described as ‘closed’ or ‘segregated’ depends on the circumstances.

The Chair and Commissioners Mason and Ryan therefore do not regard all group homes, Australian Disability Enterprises, day programs and special or separate schools as necessarily warranting the description ‘closed and segregated settings’.

Nonetheless, for the purposes of only this Volume, and specifically for the purpose of Recommendation 12.7, the Chair and Commissioners Mason and Ryan acquiesce in the use of the expression ‘closed and segregated’ to describe the settings identified above. These Commissioners make it clear that describing group homes, for example, in this Volume as ‘closed and segregated settings’ does not imply the Commissioners accept group homes are necessarily harmful to the residents’ health, safety, security, and wellbeing, or necessarily create an undue risk of harm to residents.

Recommendations

Recommendation 12.1

The Australian Government and state and territory governments should each publish a written response to the Royal Commission's *Final report* by 31 March 2024. Their responses should indicate whether the recommendations are accepted, rejected or subject to further consideration. They should include a plan for how the accepted recommendations will be implemented, the reasons for rejecting any recommendations, and a timeframe for any further consideration required.

The Australian Government and state and territory governments should table their responses in their respective parliaments and legislative assemblies.

Recommendation 12.2

The Disability Reform Ministerial Council should oversee the implementation of the Royal Commission's recommendations across the Australian Government and state and territory governments.

The Australian Government and each state and territory government should report to the Disability Reform Ministerial Council every six months. Their reports should detail the implementation status of each recommendation and raise any issues and risks.

In its 2024 report to National Cabinet, the Disability Reform Ministerial Council should identify the implementation of the Royal Commission's recommendations as one of its priorities and include it in its workplan.

Recommendation 12.3

Commencing in 2025, the National Disability Commission should table an annual report in the Australian Parliament reporting on the progress of the Australian Government and state and territory governments in implementing the recommendations of the Royal Commission.

The report should compare progress across jurisdictions.

(For details of the National Disability Commission, see Volume 5, *Governing for inclusion,* Recommendation 5.5.)

Recommendation 12.4

The National Disability Commission should lead independent evaluations of the implementation of the Royal Commission's recommendations and their effectiveness in improving outcomes for people with disability. The evaluations should examine barriers to and drivers of effective implementation and suggest measures for improvement.

The evaluations should be conducted five and 10 years after the delivery of the *Final repor*t, with reports tabled in the Australian Parliament.

Recommendation 12.5

The Australian Government and state and territory governments, through the Disability Reform Ministerial Council, should address the lack of consistent disability data by developing a nationally consistent approach to collecting disability information.

By December 2024, the Australian Government and state and territory governments should agree to a core set of questions to identify disability status to be used across all mainstream services and population surveys. This should be led by the Australian Bureau of Statistics and the Australian Institute for Health and Welfare. The questions should be co-designed with people with disability and their representative organisations, and with First Nations subject matter experts.

Recommendation 12.6

The Australian Government and state and territory governments, through the Disability Reform Ministerial Council, should address the lack of available disability data by implementing disability flags in data collections for key mainstream services.

By June 2025, the Australian Government and state and territory governments should publish an implementation plan outlining how the core set of questions will be integrated into data collections of priority mainstream services. This should be led by the Australian Bureau of Statistics and the Australian Institute for Health and Welfare.

Recommendation 12.7

The Australian Government and state and territory governments should support a strategy, led by the Australian Bureau of Statistics and the Australian Institute of Health and Welfare, to extend disability data collection:

a. to include people with disability in closed and segregated settings and those with communication support needs

b. to improve data on types of impairment

c. to improve data for intersectional analysis by enhancing data on women with disability; children and young people with disability; and First Nations, culturally and linguistically diverse, and LGBTIQA+ people with disability.

This strategy should form part of the Australia’s Disability Strategy 2021–2031 Data Improvement Plan.

Recommendation 12.8

The Australian Government and state and territory governments, through the Disability Reform Ministerial Council, should commit to long-term support to the National Disability Data Asset (NDDA).

All governments should:

a. by June 2024, commit to continuing funding to establish the NDDA as a national resource for longitudinal analysis of linked data across service systems

b. commit to publishing an annual statistical summary of the analyses of the NDDA's linked data. This should focus on data insights not available from other sources and provide transparency on projects underway. All reported data should be disaggregated as far as possible to enable intersectional analysis

c. by December 2024, commence specific data projects using the NDDA that:

- identify the factors that put people with disability at greatest risk of violence, abuse, neglect or exploitation
- demonstrate the outcomes and experiences of people with disability transitioning between systems, including:
    - education and employment, child protection and justice systems, and housing and health
    - the National Disability Insurance Scheme and mainstream services
- evaluate the accuracy of disability status collection in various service settings.

1. Delivering change

Key points

- The Royal Commission's recommendations aim to realise significant change for people with disability.
- The recommendations were developed after people with disability, their families, friends, carers and supporters told us about their experiences of violence, abuse, neglect and exploitation. Service providers and governments also told us about challenges to and opportunities for improving outcomes for people with disability.
- The Australian Government and state and territory governments should publish written responses to our *Final report* by 31 March 2024. These should indicate whether our recommendations are accepted, rejected or subject to further consideration.
- Implementing our recommendations will be complex and will require time to take effect. It will require collaboration and coordination across governments, public and private sectors and the community.
- We recommend the Disability Reform Ministerial Council oversee the implementation of our recommendations by the Australian Government and state and territory governments. In its 2024 report to National Cabinet, the Council should prioritise the implementation of the recommendations and include it in its workplan.
- An independent, transparent monitoring process is needed to ensure our recommendations are effectively implemented.
- The independent National Disability Commission should deliver an annual report to the Australian Parliament assessing the implementation of our recommendations across each jurisdiction.
- It will be important to understand the impact of our recommendations. The National Disability Commission should conduct evaluations of the effectiveness of reforms to improve outcomes for people with disability five and 10 years after the delivery of this *Final report*.

1.1. Introduction

In this *Final report*, we make a range of recommendations designed to achieve significant change for people with disability. If implemented they will help prevent violence against, and abuse, neglect and exploitation of, people with disability. Further, these changes will embed the human rights of people with disability into government policy and practices to ensure respect for their inherent dignity and individual autonomy.

Implementing our recommendations will require careful and coordinated implementation across all jurisdictions. We acknowledge this will be challenging, particularly the level of coordination and collaboration required. However, as the Australian Law Reform Commission stated in its inquiry into the *Royal Commissions Act 1902* (Cth), 'implementation of recommendations is one important measure of the effectiveness of inquiries'.[1]

This chapter has four sections, which address the need for:

- clarity in government responses to our recommendations
- coordinated implementation across jurisdictions
- independent monitoring and reporting of the progress of implementation
- evaluating the effectiveness of our recommendations in achieving change for people with disability.

1.2. Responding to our recommendations

As explained in Volume 2, *About the Royal Commission*, on 4 April 2019, the then Governor-General, His Excellency, General the Honourable Sir Peter Cosgrove AK CVO MC (Retd), issued letters patent under the *Royal Commissions Act 1902* (Cth) establishing the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability and setting out the terms of reference. Each of the six states subsequently issued letters patent or the equivalent to the nominated Commissioners in substantially the same terms as the letters patent issued by the Governor-General.[2] The Royal Commission has, in effect, been conducted as seven concurrent commissions of inquiry.[3]

Consistently with the terms of reference, our recommendations aim to realise a more inclusive society that prevents violence against, and abuse, neglect and exploitation of, people with disability. People with disability, their supporters and representative organisations, and everyone who has engaged with the Royal Commission rightly expect governments to respond to those recommendations.

We recommend the Australian Government and each state and territory government consider and publicly respond to our recommendations within six months of receiving our *Final report*. This is similar to the recommendations made by other royal commissions. For example, the Royal Commission into Institutional Responses to Child Sexual Abuse recommended a formal response from the Australian Government and state and territory governments within six months of tabling.[4] The Royal Commission into Aged Care Quality and Safety requested the Australian Government report to Parliament about its response to the Royal Commission's recommendations within three months of presenting the final report.[5] Timelines were met in both instances.

Some recommendations will be a matter for individual governments, whereas others will require consideration by all governments. We know each jurisdiction has different social, economic and demographic contexts that need to be considered. Recommendations directed at the Australian Government may also impact each state and territory differently. We anticipate governments will reflect this complexity in their responses.

It is important governments engage with people with disability in implementing our recommendations. Throughout this report, we have emphasised the importance of putting the voices of people with disability at the heart of policy making – from designing initiatives through to delivery, monitoring and evaluation.

We acknowledge governments may be unable to provide a definitive position within the recommended timeframes if a recommendation requires further consideration and engagement. In that case, governments should indicate in their response the nature of consideration required and a timeframe for a final response.

Recommendation 12.1

The Australian Government and state and territory governments should each publish a written response to the Royal Commission's *Final report* by 31 March 2024. Their responses should indicate whether the recommendations are accepted, rejected or subject to further consideration. They should include a plan for how the accepted recommendations will be implemented, the reasons for rejecting any recommendations, and a timeframe for any further consideration required.

The Australian Government and state and territory governments should table their responses in their respective parliaments and legislative assemblies.

1.3. Implementing our recommendations

The Australian Government is responsible for policy and service delivery in a number of areas directly affecting people with disability. State and territory governments are also responsible for policy and service delivery in certain areas while shared governance arrangements are in place for others. Local government also plays an important role in delivering services and infrastructure accessed by people with disability (for example, accessible recreational facilities).[6] Within each level of government, multiple agencies and departments are responsible for policies, programs and services. Improving outcomes for people with disability therefore requires action and collaboration across all levels of government, the disability sector, business organisations and the wider community.

A single coordination point should oversee the implementation of recommendations across jurisdictions. We recommend the Disability Reform Ministerial Council undertakes this role. The Disability Reform Ministerial Council is the current ministerial intergovernmental forum for disability issues. Its members include Australian Government and state and territory government ministers who have responsibility for disability policy.[7]

We recommend the Australian, state and territory governments should report to the Disability Reform Ministerial Council every six months on progress in implementing the Royal Commission's recommendations.

The Disability Reform Ministerial Council will provide a forum to:

- coordinate reporting from each jurisdiction on the implementation of recommendations
- consider implementation issues and risks, including sharing information and lessons across jurisdictions
- drive necessary actions to ensure implementation is effective.

The Disability Reform Ministerial Council reports annually to National Cabinet on progress in its workplan and priorities for the next year. National Cabinet is a forum for the Prime Minister, Premiers and Chief Ministers to meet and work collaboratively.[8] In its 2024 report to National Cabinet, we recommend the Disability Reform Ministerial Council should identify progress in implementing the Royal Commission's recommendations as one of its priorities and include it in its workplan.

Recommendation 12.2

The Disability Reform Ministerial Council should oversee the implementation of the Royal Commission's recommendations across the Australian Government and state and territory governments.

The Australian Government and each state and territory government should report to the Disability Reform Ministerial Council every six months. Their reports should detail the implementation status of each recommendation and raise any issues and risks.

In its 2024 report to National Cabinet, the Disability Reform Ministerial Council should identify the implementation of the Royal Commission's recommendations as one of its priorities and include it in its workplan.

1.4. Assessing implementation progress

In addition to reporting on whether our recommendations have been implemented, it will be important to know whether the changes have resulted in improvements in the lives of people with disability.

Volume 5, *Governing for inclusion*, emphasises the importance of independent reporting and assessment. The Productivity Commission has explained, in the context of reporting on intergovernmental agreements, that a reporting process can effectively drive actions and hold governments to account if it is transparent and comes from a credible and influential source.[9]

We recommend an independent statutory body – the National Disability Commission – be established and led by people with disability (see Volume 5, *Governing for inclusion*, Recommendation 5.5). Its role would include independently reporting on outcomes for people with disability. It would also assess progress on the implementation of *Australia's Disability Strategy 2021–2031* (ADS) and the performance of each jurisdiction. We recommend the Commission provide a comprehensive report to the Australian Parliament on outcomes for people with disability. This report would consider information from different data and reporting sources, as well as the experiences of people with disability.

The new National Disability Commission will be well placed to assess independently and report progress in implementing our recommendations across each jurisdiction. This process should build on the Commission's reporting on outcomes for people with disability.

In cases where recommendations are being implemented by multiple governments, reporting should include a comparative assessment of progress across jurisdictions. In Volume 5, we highlight the advantages of this in a federal system. Comparative assessments allow jurisdictions to learn from one another to adopt best practice approaches.[10]

For reporting to be effective, it needs to be transparent and public.[11] Reports on the implementation of our recommendations should be released to the public in a timely manner.

People with disability must play an essential role in monitoring and reporting on the implementation of our recommendations; this is in line with the obligations of Article 33 of the *Convention on the Rights of Persons with Disabilities* (*CRPD*). The National Disability Commission should engage closely with people with disability when reporting on the recommendations.

Recommendation 12.3

Commencing in 2025, the National Disability Commission should table an annual report in the Australian Parliament reporting on the progress of the Australian Government and state and territory governments in implementing the recommendations of the Royal Commission.

The report should compare progress across jurisdictions.

(For details of the National Disability Commission, see Volume 5, *Governing for inclusion,* Recommendation 5.5.)

1.5. Evaluating effectiveness

Determining whether the implementation of our recommendations has led to measurable improvements for people with disability is also important.

The impact of our recommendations may not be evident immediately; in some cases, effecting change will require long-term commitment.

We recommend the National Disability Commission undertakes formal process and outcome evaluations of the effectiveness of the Royal Commission's recommendations. These should be conducted five and 10 years after the delivery of the *Final report*, with evaluation reports tabled in the Australian Parliament.

Evaluating the effectiveness of our recommendations would assist in continuous improvement to prevent and respond to violence against, and abuse, neglect and exploitation of, people with disability. The process evaluation would address questions about what makes implementation successful. The outcome evaluation would determine the overall effectiveness of a recommendation in achieving its objective.

The questions to be considered in an evaluation should include, but not be limited to:

- To what extent have the measures taken in response to the Royal Commission's findings and recommendations been effective in addressing violence against, and abuse, neglect and exploitation of, people with disability?
- Have the recommendations met their objectives?
- What outcomes have recommendations achieved to date?
- What factors have contributed to the effectiveness of recommendations?
- What factors have limited the effectiveness of recommendations?
- How well do the recommendations address diverse experiences of people with disability?

- How well do the recommendations respond to the diverse needs and priorities of people with disability, including women and girls, First Nations people, people from culturally and linguistically diverse backgrounds, and LGBTIQA+ people?
- What further steps should be taken by governments and institutions to ensure recommendations are effectively implemented?
- What further steps should be taken to build on promising practice and ensure continuous improvement?

The National Disability Commission, as an independent disability-focused agency, would be the appropriate body to lead these evaluations and undertake engagement across service providers, people with disability, their representative organisations, advocates and supporters. In Volume 4, *Realising the human rights of people with disability*, we have proposed the Commission be established under the new *Disability Rights Act* and be independent from government policy-making and service provision. This will ensure the Commission is at arm's-length from the process of implementing our recommendations and can lead an impartial evaluation. It could draw on what it has learned from reporting on the implementation of the recommendations, and from its broader reporting on outcomes for people with disability.

The National Disability Commission should, in consultation with people with disability, determine the terms of reference for evaluations of our recommendations and the areas of particular focus.

Recommendation 12.4

The National Disability Commission should lead independent evaluations of the implementation of the Royal Commission's recommendations and their effectiveness in improving outcomes for people with disability. The evaluations should examine barriers to and drivers of effective implementation, and suggest measures for improvement.

The evaluations should be conducted five and 10 years after the delivery of the *Final report*, with reports tabled in the Australian Parliament.

Endnotes

1 Australian Law Reform Commission, *Making inquiries: A new statutory framework*, Report 111, October 2009, p 165.

2 The relevant legislation establishing the Royal Commission for each state is: *Royal Commissions Act 1923* (NSW), *Commissions of Inquiry Act 1950* (Qld), *Royal Commissions Act 1917* (SA), *Commissions of Inquiry Act 1995* (Tas), *Inquiries Act 2014* (Vic) and *Royal Commissions Act 1968* (WA). Original Letters Patent containing terms of reference were dated 17 April 2019 (NSW), 27 June 2019 (Qld), 20 June 2019 (SA), 20 May 2019 (Tas), 4 June 2019 (Vic) and 20 August 2019 (WA). South Australia issued separate letters patent to each Commissioner rather than one set to all Commissioners. Victoria's letters patent were issued by the Lieutenant-Governor rather than the Governor.

3 See *Royal Commissions Act 1902* (Cth) s 7AA.

4 Royal Commission into Institutional Responses to Child Sexual Abuse, *Final report recommendations*, December 2017, p 61.

5 Royal Commission into Aged Care Quality and Safety, *Recommendations*, March 2021, p 309.

6 Australian Government Department of Social Services, Australia's Disability Strategy 2021–2031, December 2021, pp 54–55.

7 'Disability reform ministers' meetings', *Australian Government Department of Social Services*, web page, 10 February 2023. <www.dss.gov.au/our-responsibilities/disability-and-carers/programmes-services/government-international/disability-reform-ministers-meeting>; Submissions by the Australian Government in response to Counsel Assisting's submissions in Public hearing 11 and Public hearing 15, 3 May 2022, SUB.0040.0001.0100, p 3[10]; Submissions by the Australian Government in response to Counsel Assisting's submissions in Public hearing 31, 9 March 2023, SUB.0055.0001.0005, p 7[24b].

8 'Australia's federal relations architecture', *federation.gov.au*, web page. <www.federation.gov.au/sites/default/files/2022-11/federal-relations-architecture.pdf>

9 Australian Government Productivity Commission, *Review of the National Disability Agreement*, Study report, January 2019, p 161.

10 Alan Fenna, 'Performance comparison in Australian federalism' in *A federation for the 21st century*, Committee for Economic Development of Australia, 2014, p 96.

11 Alan Fenna, 'Performance comparison in Australian federalism' in *A federation for the 21st century*, Committee for Economic Development of Australia, 2014, p 96.

2. Building the policy evidence

Key points

- High quality data and research are important for understanding the violence, abuse, neglect and exploitation people with disability experience. They are also necessary for developing good policy and holding governments and organisations to account.
- Data about people with disability is dispersed across many datasets, with at least nine different definitions of ‘disability’.
- The Disability Reform Ministerial Council should develop a nationally consistent approach to collecting disability information. There should also be wider adoption of a disability flag in data collections. This would enable the experiences of people with disability to be better understood, particularly across different services.
- As part of Australia’s Disability Strategy Data Improvement Plan, strategies should be developed to improve data collection about people with disability in closed and segregated settings, and those with communication support needs.
- The Data Improvement Plan should include better data on groups with intersecting and multiple disadvantage. It should improve data on different types of impairment; women with disability; children and young people with disability; and First Nations, culturally and linguistically diverse, and LGBTIQA+ people with disability.
- The Australian Government and state and territory governments should establish the National Disability Data Asset as a national resource for linked, longitudinal analysis.
- Data linkage helps to build a comprehensive picture of the experiences of people with disability with services such as health care, education, employment and housing. It also enables longitudinal analysis to help understand trends and provide the policy evidence for inclusive service and system design.
- The Australian Government set up the National Disability Research Partnership (NDRP) to develop a more inclusive and stronger disability research program.

2.1. Introduction

The Royal Commission had difficulty obtaining good quality data and research to underpin our work. This affected our ability to understand the nature and extent of violence against, and abuse, neglect and exploitation of, people with disability and how to respond to and prevent it.

High quality data and research are important for developing effective policy and holding governments, service providers and other organisations to account. Without this data and research, it is impossible to know the frequency of violence against, and abuse, neglect and exploitation of, people with disability, and if policy responses to prevent it are effective.

In this chapter, we look at ways to build the evidence base through better data and research. This is important for:

- developing policy for people with disability and implementing the Royal Commission's recommendations
- reporting on the implementation of our recommendations
- measuring and reporting on progress towards improved outcomes for people with disability
- supporting robust and timely monitoring, reporting and evaluations of the effectiveness of policy
- enhancing the accountability of governments for their actions through transparent information.

As we discuss in Volume 4, *Realising the human rights of people with disability*, Australia has obligations under the *Convention on the Rights of Persons with Disabilities (CRPD)*, to collect accurate and appropriate statistical and research data. Article 31 of the *CRPD* describes how the data should be collected and used to formulate and implement policies to give effect to the convention.[1]

As we explain in Chapter 1 of Volume 3, *Nature and extent of violence, abuse, neglect and exploitation*, Australia has good data on the number of people with disability through the Australian Bureau of Statistics *Survey of Disability, Ageing and Carers*.[2] However, the limitations of available data meant that we had difficulty building a full picture of the violence, abuse, neglect and exploitation that people with disability experience.

During our inquiry, we met with key agencies who hold or collect disability data. We heard about efforts across government to improve the collection and use of data about people with disability and their experiences.[3]

Particularly important is Australia's Disability Strategy Data Improvement Plan, endorsed by the Australian and state and territory ministers responsible for disability[4] and released in January 2023.[5] Its purpose is to improve the data needed to track progress against

Australia’s Disability Strategy Outcomes Framework and to support evaluations for informing policy and program development. The plan outlines the data improvement activities all levels of governments have agreed to undertake to measure the impact of the ADS on improving outcomes for people with disability.[6]

The Data Improvement Plan will:[7]

- ensure data needed to measure outcomes for people with disability is collected, shared and improved over the life of the ADS
- identify where data needs to be linked between systems to improve understanding of the impact of the ADS
- consider how linked, deidentified data can:
    - help develop more comprehensive data
    - deliver deeper insights into the pathways people with disability take through service systems and their outcomes.

We support the development of the Data Improvement Plan and note the Australian, state and territory governments’ commitment to revise it to take account of our recommendations.[8]

This chapter addresses evidence we heard about problems collecting consistent data on people with disability and their experiences of violence, abuse, neglect and exploitation. It also highlights how these data gaps hinder the case for further research or policy reforms. The lack of available data weakens the capacity of departments to build a case for additional or re-directed funding to implement such reforms.[9]

The chapter begins with a description of data sources on people with disability and the limitations of these sources. It then looks at four key ways to considerably improve disability data, including:

- by developing a national approach to collecting disability information to support the collection of better data about people with disability
- through the wider adoption of a disability flag to identify people with disability in data collections
- by extending the collection of disability data:
    - to cover groups of people with disability who are particularly at risk of violence, abuse, neglect and exploitation, but are hard to reach
    - to improve the capacity for intersectional analysis
- by establishing the National Disability Data Asset as a national resource for linked data across service systems.

The chapter then provides an overview of the current state of disability research. We acknowledge the Australian Government's initiative establishing the National Disability Research Partnership (NDRP) as the primary vehicle for developing a more coordinated approach to disability research in Australia.

2.2. Data about people with disability

Existing data sources

To support our work, particularly the development of recommendations, we have drawn upon a wide range of data sources to build a picture of the experiences of people with disability in Australia.

Data sourced from the Australian Bureau of Statistics and the Australian Institute of Health and Welfare (AIHW) has been used extensively to support our work.

For example, we used the following Australian Bureau of Statistics national survey data:

- the *Survey of Disability, Ageing and Carers (SDAC)*, which contains good data on the number of people with disability in Australia[10]
- the *Personal Safety Survey (PSS)*, which we used to describe the nature and extent of violence experienced by people with disability in Australia, including comparisons with people without disability[11]
- the *National Aboriginal and Torres Strait Islander Health Survey*, which we used to describe violence experienced by First Nations people with disability[12]
- the *Census*, which we used to understand more about specific population groups, such as people from culturally and linguistically diverse backgrounds and people who are experiencing homelessness[13]
- the *General Social Survey*, which is the only national survey we were able to use for information on both sexual identity and disability.[14]

The data we used from the AIHW largely comes from administrative data, which agencies collect during the delivery of services. Administrative data refers to data on the services delivered to people, and data about those people, such as their age and whether they have disability. Administrative data is collected by government and non-government services across areas such as health, family and community services, homelessness, police and domestic violence.

There are other data sources for information about people with disability and the supports they access. They include disability-specific agencies, such as the National Disability Insurance Agency (NDIA) and the NDIS Quality and Safeguards Commission (NDIS Commission). Agencies that provide services to people with disability among others, such as the

Department of Social Services, also collect data. Other data sources hold information on people with disability that relate to a particular policy area or service type (such as education), or a particular population group (such as First Nations people), or jurisdiction or location.

The AIHW has a legislated role to work with other agencies to develop data standards and collections across health and welfare areas, and publish statistics on this data.[15]

As part of these obligations, the AIHW publishes the *People with disability in Australia* report.[16] This report draws on more than 35 sources of data on people with disability to look at their experiences of everyday life. It includes information on housing, education and skills, justice and safety, social support, health, income and finance, and employment. The Royal Commission used this report extensively to inform our work. In its report, the AIHW highlights six key challenges with existing data sources. These are:[17]

- inconsistent definitions of disability across data sources
- poor adoption of a disability flag to identify people with disability across mainstream data sources
- fragmented, dispersed and incomplete data about services used by people with disability (specialist and mainstream)
- inability to reliably report on specific population groups within the broader disability population (often referred to as intersectionality)
- availability of relevant data collected but not collated or otherwise available for statistical purposes
- limited integration of data across settings and life area domains to examine pathways and outcomes for people with disability.

Section 2.3, ‘Importance of consistent definitions of disability’, discusses the challenges relating to inconsistent definitions of disability, with Recommendation 12.5 aimed at addressing these issues. Section 2.4, ‘Wider adoption of a disability flag to identify people with disability’, discusses the poor adoption of a disability flag and incomplete disability data, which leads to Recommendation 12.6.

Section 2.5, ‘Improving the understanding of at-risk groups’, discusses the challenges we found in relation to being unable to reliably report on specific population groups. Recommendation 12.7 is directed at resolving these issues. Finally, section 2.6, ‘Tracking population outcomes’ and section 2.7 ‘The National Disability Data Asset’, discuss the challenges related to fragmented and dispersed data that is not collated or integrated across settings and life area domains. This is addressed through Recommendation 12.8, which relates to the National Disability Data Asset (NDDA).

2.3. Importance of consistent definitions of disability

Conceptual and operational definitions of disability

The *CRPD* defines people with disability as:

> those who have long-term physical, mental, intellectual, or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.[18]

The International Classification of Functioning, Disability and Health (ICF) is the global standard for measuring functioning and disability at individual and population levels. Researchers of the ICF Australia Interest Group state that the ICF and *CRPD:*

> share common concepts, culture and terms (e.g., environment, barriers, participation), and the subject matter of rights in the CRPD can readily be mapped to the ICF domains, demonstrating broad commonality of content.[19]

The ICF recognises the interconnection between disability and environmental and personal factors, integrating the medical and social models of disability.[20] In defining disability, the ICF says disability can involve one or more of impairments to body functions or structures, activity limitations or participation restrictions.[21]

The conceptual definitions of disability used in the *CRPD* and ICF can be translated into operational definitions that allow particular 'groups of interest' to be measured for statistical purposes. Operational definitions describe the indicators that are used to measure the group and how the indicators will be measured. For example, the NDIA's operational definition of disability is:

> Total or partial loss of the person's bodily or mental functions (The Disability Act 1992). Describes a person's impairment of body or function, a limitation in activities or a restriction in participation when interacting with their environment.[22]

The NDIA uses this definition and determines a person's eligibility for the National Disability Insurance Scheme (NDIS) through their disability requirements.[23]

Where a person is identified in a data collection as being part of a group of interest, such as under an operational definition of disability, they are identified with a so-called 'flag'. Flags are used across datasets of most mainstream services to track the experiences of particular groups of people within and across different services. Disability flags can be used to help tailor services to people with disability.

Different operational definitions of disability

Across the 35 data sources used in AIHW's *People with disability in Australia,* there are at least nine different operational definitions of disability in use.[24] The NSW Government told us:

> Currently there is no single universally applied definition of disability used in Australia. Instead, a number of operational definitions of disability are used across states, territories and the [Australian Government]. Definitions vary depending on the setting and their purpose.[25]

For example, the Australian Bureau of Statistics' broad definition of disability is:

> any limitation, restriction or impairment which restricts everyday activities and has lasted, or is likely to last, for at least six months.[26]

However, the Australian Bureau of Statistics told us:

> A single definition of disability cannot satisfy all purposes. For this reason, there are several definitions available to support targeted analysis to varying degrees of specificity.
>
> ABS disability definitions are currently aligned as closely as possible across ABS collections for the varying purposes of analysis required and type of collection method used. This harmonisation is sufficient to ensure comparisons of different ABS sources and to understand disability populations in each collection.
>
> The ABS currently uses the World Health Organization ICF as the basis for the standard classification of disability in surveys.[27]

The Australian Bureau of Statistics uses three different operational definitions to capture disability information in the three surveys the Royal Commission has used extensively: the *SDAC*, the *PSS* and the *Census.* They all ask survey respondents a set of questions known as a 'module'.

The Australian Bureau of Statistics told the Royal Commission:

> the SDAC is designed to obtain detailed data about the prevalence of disability and the underlying conditions causing disability and was developed to align with international measures of disability as described in the World Health Organization International Classification of Functioning, Disability and Health (ICF). The disability identification module of the SDAC currently contains 166 questions.[28]

More information about the way disability is identified in the *SDAC* is described in Chapter 1 of Volume 3, *Nature and extent of violence, abuse, neglect and exploitation.*

The Australian Bureau of Statistics uses a set of 16 questions, known as the Short Disability Module, to identify people with disability in the *PSS*. The module applies ‘similar criteria as the *SDAC* (but in a much briefer question format) to identify people with a disability and determine their severity of restriction’.[29]

The *Census* contains four questions to identify people with disability. As the Australian Bureau of Statistics explained:

> The Census is one of the largest statistical collections undertaken by the ABS and collects information from every household in Australia to measure the number and key characteristics of people in Australia on Census night … In the Census, it is possible that a household representative completes the form on behalf of others in the household. Accordingly, unlike the Short Disability Module, the Census method of collection does not always allow for direct collection from the affected individual. Therefore, obtaining accurate information may be an issue in these circumstances … The number of questions is limited to avoid it being too onerous.[30]

In line with the Australian Bureau of Statistics Short Disability Module and the ICF, the AIHW has developed a ‘standardised disability flag’ intended for use by all mainstream services in their data collections.[31] The AIHW describes this as:

> a standard set of questions assessing a person’s level of functioning and need for support in everyday activities. These questions are based on the ICF, and are broadly consistent with the Short Disability Module questions the ABS uses in a number of its surveys. Versions of the flag have been implemented in the AIHW’s Specialist Homelessness Services Collection, the National Social Housing Survey, and National Prisoner Health Data Collection, and are being implemented within other AIHW collections.[32]

Problems of inconsistency in definitions

Having at least nine different definitions to identify disability reduces our ability to understand and respond to the experiences of people with disability. The data collected is difficult to interpret and compare. This affects how we monitor progress towards social inclusion for people with disability.

We heard evidence about this in relation to First Nations people in Public hearing 11, ‘The experiences of people with cognitive disability in the criminal justice system’. Ms Cheryl Axleby, CEO of Aboriginal Legal Rights Movement in South Australia, said:

> it’s important just to point out there is no focused population-based survey that the prevalence, profile and outcomes for Aboriginal and Torres Strait Islander people with disability … the ABS Survey of Disability, Ageing and Carers provides one primary source of population data, and the ABS National Aboriginal and Torres Strait Islander Social Survey provides another, but there are significant differences in [reporting] how many of my people have a disability.[33]

The Australian Bureau of Statistics *SDAC* estimates 4.4 million Australians have a disability, with 2.4 million under the age of 65. This is based on the following definition of disability: 'any limitation, restriction or impairment which restricts everyday activities'.[34] The *Census* has a narrower definition of disability. It identifies 1.5 million people as having 'profound or severe core activity limitation', requiring assistance with core activities.[35]

The Australian Bureau of Statistics recommends using the *SDAC* as the source of disability prevalence data in Australia. However, it says the *Census* provides 'a rich snapshot of all people in Australia on Census night, and is the leading source of information for small population groups and areas'.[36]

If *Census* data is used to estimate the proportion of people with disability in Australia, it will underestimate the prevalence of disability. This is due to its narrower focus on those requiring assistance with core activities.

The Australian Bureau of Statistics states that *Census data:*

> helps service providers and governments plan what local facilities, services and support are required, such as in-home support, respite care and support to carers.[37]

Similarly, the Australian Bureau of Statistics states the *Census* is used to provide context about social and economic factors in people's lives:

> The large number of questions in the SDAC to assess disability levels limits the time available to ask respondents additional questions about the social and economic context of their lives. Therefore, we use the information collected in the Census to provide some of this context for people with a core activity need for assistance.[38]

The different definitions and the discrepancy between the number of people with disability identified through the *Census* and the *SDAC* mean there is not enough information about the social and economic circumstances of most people with disability in Australia. This can make it harder to plan services for those people.

As another example, in their research paper, *Identification of people with disability in linked administrative data,* researchers from the University of Melbourne concluded that key administrative datasets underestimated the prevalence of disability compared with the *SDAC*. They identified two likely reasons for the difference in prevalence:

> (1) differences in the operational definitions of disability between SDAC and in the administrative data sources, and
>
> (2) differences in the characteristics of people in the SDAC sample and those in the administrative data population, which is based on access to support services and payments (i.e., not all people with disability receive support payments or are NDIS participants, for example).[39]

Different operational definitions of disability cause confusion among those asking about and among those being asked about disability.

Ms Jennifer Westacott AO, Chief Executive of the Business Council of Australia, provided evidence in Public hearing 19, ‘Measures taken by employers and regulators to respond to the systemic barriers to open employment for people with disability’. She told us about barriers to collecting consistent data in employment settings:

> the definition is different between the ABS, it’s different between the discrimination acts, it’s different between the employment services. So I think getting a common definition would be helpful. I think certainly when I’ve asked employers about this, there is a bit of anxiety about asking people about whether or not that in and of itself is a breach of a discrimination provision, and so I think, again, that would be helpful.[40]

Core questions to identify disability status

Approaches vary across datasets, partially out of necessity. For instance, some definitions are tied to eligibility for services. However, there is room for greater alignment and consistency in the collection and presentation of data.

We propose the Australian Government and state and territory governments should develop and implement a nationally consistent approach to collecting disability information. This approach should be aligned to the ICF but will enable different operational definitions of disability to remain in use.

The approach will require the development of a uniform set of questions that can be asked of individuals to identify disability. These questions should be asked when individuals use services or when they respond to population surveys. Uniform standards should also be established to determine what responses will indicate a person has a disability.

We propose the Australian Bureau of Statistics and the AIHW should lead this initiative, building on their expertise in developing datasets. Their leadership will be linked to their role supporting the Department of Social Services in the technical design of the National Disability Data Asset (NDDA).[41]

The Australian Bureau of Statistics is already collaborating with the AIHW to develop ‘technical guidelines and methodology to help to better define and understand disability across datasets’.[42]

The AIHW notes ‘these methodologies would then be employed within the NDDA and in other work to support the consistent reporting of statistics on people with disability across all sectors’.[43]

We also endorse the work of the AIHW on a standardised disability flag, which is further discussed in section 2.4, ‘Wider adoption of a disability flag to identify people with disability’. The questions contained within this flag could provide a basis for a nationally consistent core set of questions. The AIHW notes its standardised disability flag was intended for wider use:

> The set of questions [of the standardised disability flag] is designed to provide consistent and comparable information across mainstream services in all Australian jurisdictions over time and across administrative data collections.[44]

As we note in section 2.2, ‘Data about people with disability’, the Australian Bureau of Statistics uses varied sets of questions to collect information about disability, depending on the purpose of the dataset and the detail required. Similarly, a ‘short-form’ set of questions could be used in the implementation of the flag where less detail is required. The short-form questions could be used in standard datasets, while the long-form could be used where more detail on the individual’s disability and their needs are important to the dataset.

Co-design approach

In line with Article 33 of the *CRPD*[45] and our *Vision for a more inclusive Australia*, a critical component of this work is to ensure the core set of questions is co-designed with people with disability and their representative organisations. This includes Disabled People’s Organisations Australia and Disability Representative Organisations. First Nations people with disability and their representative organisations should be included in the co-design process.

Co-design is important to:

- reduce concerns about confidentiality
- ensure the questions are respectful, safe and appropriately drafted
- ensure the questions are presented in a way most likely to elicit informative responses from respondents.

Co-design will assist in reducing concerns around disclosure of personal information. People with disability may be more willing to provide information if they can see governments are responding to their concerns. Research conducted by the Social Policy Research Centre at the University of New South Wales concluded:

> Good practice at a system level also involves the collection, analysis and reporting of data that can inform system design. While there is no legal mandate to share information about cultural identity or disability, the importance of data to inform system and service design cannot be denied. Any data collection must be done in a meaningful, considered, safe, and respectful way to encourage sharing of information about disability and culture, and ensure privacy is maintained.[46]

People with disability need to be comfortable with the questions asked and be given appropriate information to understand the purpose of the questions. The research by the Social Policy Research Centre highlighted that:

> The frequency and scope of data collection … could be improved but must be mindful of language and sensitivities around sharing information about disability. Where data is

> collected, it must include an explanation about the purpose of data collection, whether data will be identifiable, to ensure people understand that data provided is not used to discriminate [against] them in the future.[47]

Ms Debbie Mitchell PSM, Deputy Secretary, Disability and Carers, Department of Social Services, gave evidence at Public Hearing 31, 'Vision for an inclusive Australia'. Ms Mitchell agreed data collection methods should be co-designed by people with disability and should be trauma-informed and culturally responsive.[48]

Consistent collection of disability information will not limit the right of people with disability to choose whether to disclose their disability status. They will retain this right.

Recommendation 12.5

The Australian Government and state and territory governments, through the Disability Reform Ministerial Council, should address the lack of consistent disability data by developing a nationally consistent approach to collecting disability information.

By December 2024, the Australian Government and state and territory governments should agree to a core set of questions to identify disability status to be used across all mainstream services and population surveys. This should be led by the Australian Bureau of Statistics and the Australian Institute for Health and Welfare. The questions should be co-designed with people with disability and their representative organisations and with First Nations subject matter experts.

2.4. Wider adoption of a disability flag to identify people with disability

Poor identification of people with disability in datasets

In addition to the challenges of inconsistent definitions of disability, the Royal Commission faced difficulty in understanding the experiences of people with disability in accessing health care, education, housing, community and other services. This is because people with disability are not always identified as having a disability when they access services.

The deficiency of information about people with disability is evident in the Specialist Homelessness Services data collected by the AIHW. While the Specialist Homelessness Services collection identifies 9 per cent of clients as people with disability,[49] a data linkage project led by the Department of Social Services has demonstrated the proportion is far higher.[50] This means we are unable to fully understand the specialist homelessness services people with disability are using.

We have also heard about issues with the collection of data on people with disability in the criminal justice system.[51] For example, research commissioned by the Royal Commission found:

> The lack of capacity for effective data collection, analysis and reporting about people with disability interacting with police in Australian police databases, poses a significant challenge for an accurate understanding of the nature of police responses to people with disability.[52]

There are also inconsistencies between states and territories. The Child Protection National Minimum Data Set, for example, collects information on child protection in Australia each year. The AIHW told us:

> The child protection sector (which includes out-of-home care in our collections) has been attempting to collect disability status for many years. However, the coverage is currently limited to six jurisdictions (largely from longer out-of-home care stays) and the data that has been collected has been inconsistent between jurisdictions.[53]

In addition to the consequences identified above, poor identification of people with disability in data can have other serious outcomes. For example, it may result in the infringement of the human rights of people with disability and problems understanding who has been affected by emergency situations. In Public hearing 5, ‘Experiences of people with disability during the ongoing COVID-19 pandemic’, Commissioners found:

> Because of the deficiencies in the collection and dissemination of data, it is not possible to obtain a complete or accurate picture of the infection and mortality rates from COVID-19 for people with disability throughout Australia.
>
> The failure to collect and disseminate national data on the rates of infection and death from COVID-19 for people with disability is inconsistent with Australia’s obligations under article 31 of the [*CRPD*].[54]

While it was designed for implementation in mainstream services, uptake of the AIHW standardised disability flag has been slow. The AIHW said:

> A wider implementation of such flags, coupled with regular supply of these data for national collation and reporting, would improve the ability to report more comprehensively on people with disability. For example, the addition to, or improvement of, disability flags in existing national child protection, out-of-home care and youth justice data collections would improve visibility of children with disability in these systems.[55]

A submission from the Royal Australasian College of Medical Administrators similarly recommended extending the use of a disability flag across all mainstream services as one way to improve the quality of data on disability outcomes.[56]

However, the AIHW is unable to mandate the consistent collection of data items by the Australian Government or state and territory governments.[57]

Barriers to implementing a disability flag

There are a number of barriers to implementing a disability flag in services.

Barriers to asking individuals about their disability status

The AIHW noted service staff, such as those on the front line, may not fully understand disability or know how to question people with disability appropriately.[58] As one interview participant in a Royal Commission study observed, 'There's a tendency not to ask … you've got to find a sophisticated way of doing that'.[59]

Data collection also requires time. For busy front-line staff, collecting data competes with a long list of other priorities and data quality may suffer as a result. For example, the AIHW's homelessness services data reports more people with 'unknown' disability status than people with disability.[60] The AIHW told us staff may be unable to collect data about disability because they are busy dealing 'with a lengthy backlog of requests for additional data items and data supplies by funders, program management and other external interests'.[61]

The AIHW also said asking people if they have a disability is not necessarily a priority for service delivery staff. For example, when an individual presents to an emergency department, the focus is understandably on information relevant to triage and medical care. Information about disability can be sought later to support subsequent treatment, service delivery and referral, but often may not be collected.[62]

Service staff may also be confused about who should collect the data and why they should collect it. This can mean they place less importance on collecting information about disability status.[63]

The AIHW also noted reasons why it may not be appropriate to collect disability information. This includes contested encounters in justice settings, or where service users are unaccompanied children or are traumatised, or both.[64]

Barriers around disclosure of disability information by people with disability

There is a range of barriers to disclosure of disability, and these barriers may vary for each person. For example, a person may not see themselves as having a disability. They may feel fear or shame about disclosing personal information or may have privacy concerns about the use of their data.[65]

The Australian Public Service Commission recognised these concerns in the Australian Public Service Disability Employment Strategy:

> Employees with disability often choose not to share their disability status in HR systems. This may be due to concerns around stigma, privacy, how the data might

> affect their affect their career, and how they might be treated differently … We must be clear about what is being asked for, how this data will be used, and why it is being collected. We should also ensure employees understand how they may benefit from sharing their disability status in HR systems. This data should be collected in a consistent manner across the APS.[66]

Barriers to recording disability information

There are also technical challenges in recording and collating disability information. These include IT system changes, training for staff to ensure consistent and accurate capture of records in systems, and other efforts to ensure data quality.[67]

The sophisticated systems needed to handle this data can be expensive.[68] Governments sometimes outsource data collection and storage. This can involve multiple systems that may not be integrated, leading to more inconsistencies.[69]

Barriers to using data to infer disability status

Where a dataset does not provide information about disability, disability can be inferred through proxy measures. However, these vary in reliability. A common proxy is a person's 'use of disability services'.

For example, the AIHW uses Disability Support Pension (DSP) recipient status as a proxy for disability status in analysing how people with disability use medical services.[70] Similarly, the AIHW intends to use NDIS participation as a proxy measure for disability status in child protection analysis.[71]

However, receipt of the DSP or participation in the NDIS are not sufficient proxy indicators for disability. Not all people with disability meet the eligibility requirements for the DSP or NDIS participation. For example, the Australian Bureau of Statistics estimates that in 2018 there were approximately 2.4 million people aged 0 to 64 years with disability in Australia.[72] However, as at 31 December 2022, approximately 573,342 people with disability in Australia were NDIS participants.[73] Using these measures as proxy indicators risks excluding a large number of people with disability from the relevant group.

There is also a temptation to rely on clinical diagnoses as an indication of disability, particularly where only health information is available. However, this approach risks entrenching the problems of the medical model of disability (described in our *Vision for a more inclusive Australia)*, such that disability can only be identified through a clinical diagnosis.

Proxy indicators, such as 'use of disability services', are able to be used by connecting deidentified data, in a process known as 'data linkage'. For example, the AIHW links data concerning the use of medical services by people with disability to DSP data. However, as described in section 2.6 'Tracking population outcomes', sharing and linking data across agencies presents challenges.

Implementation plan for disability flags

The Australian Government and state and territory governments should develop an implementation plan outlining how the agreed core set of questions identifying disability status (discussed in Recommendation 12.5) will be used across key mainstream services. The implementation plan should be developed in line with, or as part of, Australia's Disability Strategy 2021–2031 Data Improvement Plan and incorporate consultation with data providers. Governments should set milestones and key performance indicators as part of this implementation plan, and report against them.

The most important mainstream services for implementing a consistent approach to data collection for people with disability are:

- health
- education
- criminal justice
- child protection and out-of-home care
- housing and homelessness.

In addition, we expect new national datasets to include a disability flag where appropriate. This includes any new prototypes, such as the work the AIHW is undertaking to address the lack of national data on specialist family, domestic and sexual violence services.[74]

Other datasets funded by the Australian Government, such as the Household, Income and Labour Dynamics in Australia (HILDA) Survey, should also include the consistent disability identifier.

Addressing barriers to implementation

The implementation plan will need to consider the specific challenges to implementing a consistent approach to collecting disability information in data collections for mainstream services.

The AIHW told the Royal Commission about its experience developing and investing in the 'National best practice guidelines for collecting Indigenous status in health data sets'.[75] The AIHW suggested the lessons from the development of this tool could be applied to improve the capture of disability information in administrative data.[76] These include:[77]

- supporting those responsible for the initial collection of data to understand why the data is important and how to ask the question
- supporting system changes to allow capture of data
- incentivising services to collect the primary data through resourcing and funding

- ongoing monitoring and evaluation to identify gaps in uptake
- ensuring the model does not interfere with primary service provision
- working with services to identify the right time to ask disability status questions.

Service staff should inform people with disability that the service they receive will not be affected by sharing their disability status. Staff should be provided with standard wording to explain what data is collected, how it will be used and the need for informed consent.[78]

The AIHW provides mainstream services with a data collection guide on its standardised disability flag.[79] This guide provides advice about the most appropriate ways in which to incorporate the flag in day-to-day operations. The AIHW Disability Unit also provides advice to data custodians who are considering including the standardised disability flag or related data items in their data collection.[80] We expect these advisory services could be expanded when necessary in implementing a consistent approach to collecting disability information.

Finally, the AIHW should provide guidance on how to resolve difficulties in comparing and aggregating data. This could include mapping different definitions, providing information on how the definitions can and cannot be used together, and plain language explanations of the differences in reporting on disparate datasets.

Once established, the Australian Government and state and territory governments should publicly report on progress against the implementation plan. This could be, for example, through the ADS 2021–2031 Data Improvement Plan reporting processes.

Recommendation 12.6

The Australian Government and state and territory governments, through the Disability Reform Ministerial Council, should address the lack of available disability data by implementing disability flags in data collections for key mainstream services.

By June 2025, the Australian Government and state and territory governments should publish an implementation plan outlining how the core set of questions will be integrated into data collections of priority mainstream services. This should be led by the Australian Bureau of Statistics and the Australian Institute for Health and Welfare.

2.5. Improving the understanding of at-risk groups

The AIHW identified key data gaps in its report *People with Disability in Australia*. This includes gaps in data about people with disability who:[81]

- are First Nations people
- live in rural and remote Australia

- live in care settings, such as people living in group homes
- are LGBTIQA+ people
- are culturally and linguistically diverse
- have experienced abuse
- have experienced discrimination
- are experiencing homelessness.

In this section, we focus on groups of people with disability who are particularly at risk of violence, abuse, neglect and exploitation.

Collecting data on hard-to-reach groups

We heard about and from groups of people with disability who may be at particular risk of violence, abuse, neglect and exploitation (see Volume 3, *Nature and extent of violence, abuse, neglect and exploitation*. These groups include people with disability who live, work or are educated in closed and segregated settings, such as group homes, Australian Disability Enterprises, day programs, special schools, youth detention facilities and prisons. It also includes people with disability who have communication support needs, such as people with cognitive disability who require support to understand information, and people with disability who have other needs, such as requiring an interpreter or support from a support worker.

Limited data available on hard-to-reach groups

Limited data is available about people with disability in closed and segregated settings and those with communication support needs. The limitations make it difficult to assess the nature and extent of violence against, and abuse, neglect and exploitation of, these groups.

Improving data collection on these groups of people will contribute to a better evidence base on disability-specific forms of abuse. These include overuse and misuse of psychotropic medication in people with intellectual disability;[82] co-resident violence and abuse in group homes;[83] the violation of reproductive rights;[84] and denial of choice and control through inappropriate reliance on guardianship and administration.[85]

The difficulties of data collection in settings such as supported disability accommodation facilities are well known. For example, the Australian Bureau of Statistics *Personal Safety Survey (PSS)* generally collects quality data on the prevalence of violence and abuse but:

> The survey is not administered to the estimated 201,100 adults with disability or a long-term health condition residing in cared accommodation, who comprise 1.1% of the adult population. Furthermore, data cannot be collected from the estimated 24,900 adult household residents with a communication disability who cannot be understood at all by someone they do not know, who comprise 0.1% of the adult population.[86]

Dr Claire Spivakovsky, from the School of Social and Political Sciences at the University of Melbourne, gave evidence in Public hearing 3, ‘The experience of living in a group home for people with disability’. She attributed the lack of data about group homes to limitations in large-scale data collection including what are often described as ‘gatekeeping’ practices that prevent public access to residents of group homes. Dr Spivakovsky said:[87]

> Sometimes there is a decision that a person is unable to speak for themselves, and so someone else will stand in for them. But then it seems that the questions around violence are not asked because it’s not coming directly from the person. So we lack a lot of quantitative data.[88]

During Public hearing 29, ‘The experience of violence against, abuse, neglect and exploitation of people with disability from culturally and linguistically diverse communities’, Mr Dominic Hong Duc Golding from the National Ethnic Disability Alliance said closed settings are particularly difficult for data collection agencies. Dr Golding said:

> One of the other things is that closed settings – of course, ABS personnel just can’t rock up to a group home and go, hey, I would like to collect data about your household.[89]

Information before us has also highlighted the challenges of collecting data from people with disability who require support to communicate. The Australian Bureau of Statistics states, in relation to administering the *PSS:*

> Where a respondent required the assistance of another person to communicate with the interviewer, proxy interviews were conducted for a limited amount of the survey and this data was not retained on the final weighted file. Therefore it is likely that the PSS will under-represent those with a profound or severe disability.
>
> …
>
> Approximately 33% of respondents who reported a profound/severe disability, were not included in the final sample due to proxy use, or opting out.[90]

The safety of the respondent is a paramount concern when data is collected in certain settings. In particular, proxies may be used to answer on behalf of the person with disability. In research carried out for the Royal Commission, the Centre of Research Excellence in Disability and Health advised that proxies must be used carefully.

The research centre advised that:

> While the use of a proxy is used for some sections of the PSS and in other ABS surveys, employing this strategy must be carefully balanced against consideration for the safety of participants, particularly in relation to when a respondent may be living and/or being assisted by a perpetrator.[91]

These issues must be addressed to ensure people with disability in closed and segregated settings and those with communication support needs are represented in data.

Improving data on hard-to-reach groups

Under the *National Plan to Reduce Violence Against Women and their Children 2010–2022*, the Department of Social Services funded the Australian Bureau of Statistics to 'review and assess current and potential data holdings about experiences of violence towards persons with disability'.[92]

The Australian Bureau of Statistics found:

> where the particular policy or research question requires information about persons with disability living in health care establishments, or for persons with profound or severe disability, alternative data collection methods to the PSS are required.[93]

The Australian Bureau of Statistics suggested that administrative data, qualitative research studies and specially designed quantitative surveys could complement existing population survey data.[94]

The Australian Bureau of Statistics is considering extending the *SDAC* to include questions about abuse and neglect not currently captured by the *PSS*. This includes questions about abuse and neglect relating to individual needs and supports.[95]

New data collections may also be required to include people with disability in closed and segregated settings. These collections may require bespoke methodologies to safely collect information from people with disability in those contexts about violence, abuse, neglect or exploitation they have experienced. People with disability, their advocates and their representative organisations could advise on the development of these methodologies.

New or extended data collection would require specific guidelines for recognising the highly sensitive nature of data on violence, abuse, neglect and exploitation, and the need to protect people from whom information is acquired.

We acknowledge that organisations such as the Australian Bureau of Statistics take care to ensure their data collection methods protect the safety and privacy of people with disability. However, no best practice guidelines for doing so are in force. The Centre of Research Excellence in Disability and Health suggested co-designed guidelines could help improve the safe collection of data about people with disability:

> co-designing guidelines about appropriate ways of collect[ing] data from people with disability with respect to safety, information access (for example, informed consent) and the use of technology to facilitate communication access [could improve the representation of people with disability in national surveys].[96]

The Victorian Government has developed data collection standards for family violence services to guide the collection of data involving people with disability.[97]

Any new data collection strategy needs to reflect an understanding that sharing experiences of violence, abuse, neglect and exploitation can perpetuate trauma. In her evidence at Public hearing 17, ‘The experience of women and girls with disability with a particular focus on family, domestic and sexual violence’, Ms Vanamali Hermans, Policy and Projects Officer at Women with Disabilities Australia, told us how certain groups may find sharing such information particularly traumatic:

> So, you know, for many women with intellectual disabilities, cognitive impairment, Aboriginal and Torres Strait Islander women in particular, there is a really specific risk of trauma associated with telling, for instance, a local area coordinator your story. So that needs to be part of an effective gender strategy for the NDIS.[98]

The Australian Government and, where appropriate, state and territory governments should prioritise and agree to a data collection strategy that maintains the safety of people with disability and recognises the risk of retraumatisation.

Collecting data on groups with intersecting and multiple disadvantage

Efforts are also needed to improve intersectional analysis of violence, abuse, neglect and exploitation experienced by people with disability. This will require increasing the visibility of key groups in data collections. This means better collection and reporting of data that can be broken down for analysis. This should improve data on different types of impairment; women with disability; children and young people with disability; and First Nations, culturally and linguistically diverse, and LGBTIQA+ people with disability.

As is discussed earlier in this volume, article 31 of the *CRPD* describes how States Parties should collect and use data to formulate and implement policies to give effect to the *CRPD*. The CRPD Committee has recommended Australia develop a national disability data collection framework, paying particular attention to groups with intersecting and multiple forms of disadvantage:

> The Committee recommends [Australia] … develop a national disability data framework to ensure appropriate, nationally consistent measures for the collection and public reporting of disaggregated data across the full range of obligations contained in the Convention, especially with regard to women, children and Aboriginal and Torres Strait Islander persons with disabilities.[99]

The *Economic cost of violence, abuse, neglect and exploitation of people with disability* report, commissioned by the Royal Commission, similarly concluded:

> understanding how disability intersects with other demographic groups is difficult. Better collection and publication of disability-disaggregated data will build a better understanding of disability policy and outcomes.[100]

The utility of administrative data depends on the context in which the data is collected. Data collected from users of a service will represent only people accessing that service. We heard from the AIHW that people with disability from disadvantaged communities ‘can have difficulties in accessing these supports and payments at a level equivalent to the level of need in that population’.[101] As a result, we are unable to rely on administrative data to understand the experience of many people with disability from those communities.

Even survey data from nationally representative samples may not produce reliable insights for different groups of people with disability. Larger-scale surveys are expensive to undertake and limited funding can often result in small sample sizes. It is difficult to extrapolate insights derived from smaller samples to the larger population with an appropriate level of confidence.[102]

Different types of impairment

The nature of a person’s impairment can significantly affect their experiences, support needs and opportunities for inclusion. For example, as discussed in Volume 3, *Nature and extent of violence, abuse, neglect and exploitation*, people with intellectual and psychosocial disability are at greater risk of violence, abuse, neglect and exploitation.

Limited data is available on the differential impact of different impairments on the lives of people with disability.

A report prepared for Inclusion Australia suggests there is limited publicly available data on the prevalence of specific conditions (such as Down syndrome, Fragile X syndrome) and of co-morbidity among people with disability. In addition, there are gaps on the number of people with intellectual disability participating in education and skills training, living in different types of accommodation, or who are under guardianship and financial management.[103]

In Public hearing 4, ‘Health care and services for people with cognitive disability’, we heard evidence about the need for improved system-wide collection and analysis of data on the health needs of people with cognitive disability.[104] Professor Julian Trollor, Professor in the School of Psychiatry at the University of New South Wales, told us:

> if we look at the accuracy of coding of the presence of intellectual disability in health datasets alone, we see very poor identification of those individuals within that system.[105]

He supported routine reporting on health outcomes for people with intellectual disability and those on the autism spectrum, as well as reporting on how the health system interacts with other supports.[106]

Women with disability

In Volume 3, *Nature and extent of violence, abuse, neglect and exploitation*, we discuss how women with disability experience violence and abuse more frequently than women without

disability, and experience different types of violence compared
to men with disability.

In Public hearing 17, Dr Jacoba Brasch QC, the then President of the Law Council of Australia, explained that inconsistent definitions of family violence across different jurisdictions has an impact on the collection of robust data:

> I have a great concern that we are comparing apples with oranges at times. There are some offences that are located – for example, strangulation, in some states and territories, that is in the Criminal Code, or the equivalent. Some is in the domestic violence [legislation]. It troubles me the statistics are not robust because we are comparing apples with oranges.[107]

The NDIA does not hold structured data on the number of NDIS participants who are women and children and are also victim-survivors of family and domestic violence.[108] Tess Moodie, Project and Policy Officer at Women with Disabilities Australia said:

> NDIS workers and staff [are] in prime positions to be able to identify when women with disabilities are experiencing violence. But we don't believe that they're currently equipped to do this effectively or properly. There are no, at the moment, substantial screening processes or assessment tools in place for them to use to be able to detect that.
>
> A standard question, you know, by an NDIS worker of, 'Are you experiencing domestic or family violence' might not be useful for women with disabilities because our experiences of violence are so broad, diverse, complex and in different settings.
>
> And those sort of questions might not identify the more hidden forms like coercive control, all the restrictive practices, or things like, you know, restricting food or neglecting care. So we really think, at WWDA, that it's important that there's a regular routine screening process to detect this, whether that's during the application process, whether it's during planning meetings or coordination of supports or service provision, or plan review meetings.[109]

In addition to known data gaps, it is likely some data may underestimate the experience of women with disability in experiencing family or domestic violence. For example, mothers with disability, particularly those with cognitive disability, are also more likely to have their children removed. Fear that a child might be removed discourages mothers from disclosing or seeking support for domestic and family violence.[110]

We welcome the initiatives underway to improve data collection on women through the *National Plan to End Violence against Women and Children 2022-2032*, which prioritises 'the critical role of effective research, data and evaluation'.[111] The first Action Plan of the *National Plan to End Violence against Women and Children 2022-2032* is due to be released in early 2023.[112] A dedicated Aboriginal and Torres Strait Islander Action Plan is also in development. These plans may go some way to addressing data gaps concerning women (irrespective of disability status).

Nonetheless, we consider a broader strategy for collecting data concerning the experiences of women with disability is still required.

Children and young people with disability

The Centre of Research Excellence in Disability and Health told us there is limited robust data on the nature, extent and impact of violence and abuse against children and young people:

> While the PSS collects information about experiences of physical and sexual abuse before the age of 15, these data are not designed to estimate population level prevalence of violence and abuse for children and young people. Rather this separate (optional) module is designed to be used in conjunction with information collected in other parts of the survey to analyse relationships between physical and sexual abuse before the age of 15 and later experiences of violence as an adult. There are insufficient numbers in the sample to reliably test this relationship for people with disability.[113]

The Australian Bureau of Statistics advises caution when interpreting *PSS* data about physical or sexual abuse before the age of 15. This is because the survey:[114]

- does not include persons aged less than 18 years
- records disability status at the time of the survey, which does not necessarily indicate whether the person had a disability at the time the violence occurred.

The lack of data on children and young people with disability significantly hampers efforts to prevent and respond to family, domestic and sexual violence.

We heard about the paucity of data on how restrictive practices are used in schools 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'.[115] Associate Professor Shiralee Poed, from the School of Early Childhood and Inclusive Education at Queensland University of Technology and an Honorary Principal Fellow of the Melbourne Graduate School of Education at the University of Melbourne, told us there is a 'lack of information or data available to identify the circumstances in which restrictive practices are used'.[116]

We welcome the initiatives underway to improve data collection on children through the *National Plan to End Violence against Women and Children 2022-2032.*[117] However, in our view, additional measures are required to collect reliable data on the experiences of children and young people with disability.

First Nations people with disability

We examined the unique challenges First Nations people with disability face in Volume 9, *First Nations people with disability*. However, it has been difficult to obtain statistical information on their experiences through administrative or survey data.

The best source of data on disability in Australia, the *SDAC*, was not designed or tested specifically to collect data on the First Nations population.[118] The Australian Bureau of Statistics also acknowledges that 17 per cent of the First Nations population is excluded from the survey because they live in remote areas.[119] Similarly, the *PSS* does not collect data on First Nations status.[120] This limits our understanding of the violence and abuse experienced by First Nations people with disability.

The Australian Bureau of Statistics *National Aboriginal and Torres Strait Islander Health Survey (NATSIHS)* does provide data on the prevalence of disability among First Nations people. However, it lacks the detail necessary to understand the violence, abuse, neglect and exploitation faced by First Nations people with disability.

In Public hearing 17, 'The experience of women and girls with disability with a particular focus on family, domestic and sexual violence', we heard from Ms Thelma Schwartz, Principal Legal Officer of the Queensland Indigenous Family Violence Legal Service, a member service of the National Forum for Family Violence Prevention Legal Services. She said, in relation to First Nations women and girls, and particularly those with disability, 'we are not seen. We are ignored. We are an add on, we are a tick and flick'.[121]

The Australian Bureau of Statistics told us it is 'committed to undertaking further investigations … on the appropriate collection of violence statistics from Aboriginal and Torres Strait Islander people'.[122] For the 2022–23 *NATSIHS*, the Australian Bureau of Statistics established an expert advisory panel to develop questions about violence. The panel made several recommendations for collecting this type of data in the future. These include addressing data collection barriers, such as fear of retribution and personal or family shame. It also includes conducting the survey in a culturally safe and appropriate manner, and employing First Nations people with experience in collecting this type of information. The panel also recommended offering respondents support after participating in the survey.[123]

The AIHW told us how the National Disability Data Asset (NDDA) Pilot sought to obtain accurate data on First Nations peoples:

> as part of the NDDA Pilot, the NDDA partners established advisory arrangements with First Nations representatives, to assist with the interpretation of results arising from the NDDA pilot phase.[124]

Preliminary findings from the NDDA test cases identified several reasons why administrative data may not accurately reflect disability among First Nations peoples:[125]

- There is no word for 'disability' in traditional languages. First Nations communities talk about individuals in the context of enabling them, not in deficit terms.
- People may not want to identify as a First Nations person to a government service provider.
- Remote and very remote areas lack services, resulting in unmet needs and chronic underestimates of First Nations people with disability.

- There is a lack of culturally appropriate engagement with people seeking help, which may result in disengagement from services and non-identification as a First Nations person.
- Failure to ask the right questions or use the right language may hide disability. For example, if a lead tenant does not identify anyone in their household as having disability, a housing service might not provide the required support.

In Public hearing 16, ‘First Nations children with disability in out-of-home care’, we heard about the Indigenous Data Sovereignty approach to data collection. Data sovereignty involves both access by First Nations people to government data, and building infrastructure for First Nations people to control data from its collection through to use and dissemination.[126] Dr Paul Gray, Co-Chair of Family Matters, told us Indigenous Data Sovereignty also involves ensuring ‘data systems are aligned to the perspectives, to the priorities and to the aspirations of Aboriginal and Torres Strait Islander people’.[127]

During Public hearing 4, Dr Scott Avery told us about his work linking disability data and data on First Nations people. He uses a method that links stories or ‘yarning pieces’ with individual statistical profiles, combining lived experience with the data collected. Dr Avery said this was a way to ensure the human story and administrative data validated one another.[128]

These issues must be considered in any strategy to strengthen data on violence against, and abuse, neglect and exploitation of, First Nations people with disability.

Data gaps regarding First Nations people with disability could be addressed through Australia’s Disability Strategy 2021–2031 Data Improvement Plan, which includes actions to address priority reforms in the National Agreement on Closing the Gap.[129] For example, New South Wales told us about its data improvement activities designed to meet its obligations in relation to the National Agreement on Closing the Gap:

> One of the key action areas under NSW Closing the Gap Implementation Plan 2022–2024 is designing an Indigenous Data Sovereignty and Indigenous Data Governance model to increase Aboriginal communities’ sovereignty over data about Aboriginal people. In the 2022–23 NSW Budget, as part of its delivery of Closing the Gap, the NSW Government is investing $47 million to support strong data and governance to drive the Government’s partnership approach with Aboriginal communities.[130]

People with disability from culturally and linguistically diverse backgrounds

Data is limited on the prevalence of disability among culturally and linguistically diverse communities. This is due to varying definitions of cultural and linguistic diversity and of disability.[131] In Public hearing 29, we also heard evidence about the limited data on violence against, and abuse, neglect and exploitation of, people with disability from culturally and linguistically diverse communities.[132]

In his evidence at Public hearing 29, Mr Dominic Hong Duc Golding from the National Ethnic Disability Alliance told the Royal Commission that many Australian Bureau of Statistics surveys are English-based questionnaires, which can mean that people who do not speak English are excluded from data collections.[133]

The Australian Bureau of Statistics *Standards for Statistics on Cultural and Language Diversity* provides a framework for collecting and disseminating data on cultural and language diversity. It provides the following cultural and language indicators: 'Country of birth of person', 'Main language other than English spoken at home', 'Proficiency in spoken English' and 'Indigenous status'.[134]

These concepts are adopted in the *Survey of Disability, Ageing and Carers (SDAC)* and the *Personal Safety Survey (PSS)*. However, the Centre of Research Excellence in Disability and Health told us culturally and linguistically diverse cohorts are likely to be 'significantly underrepresented' in the *PSS:*

> Even using the least restrictive criteria ('speaking English 'not well' or 'not at all well'') the numbers of people in the PSS who report cultural and linguistic diversity and disability are too small to produce reliable prevalence estimates.[135]

A small proportion of respondents with low proficiency in spoken English completed all of the *PSS* questions. Because the *PSS* relies on interviews, the lack of available interpreters means the *PSS* provides limited insights on the violence and abuse experienced by people with disability from culturally and linguistically diverse communities.[136]

Representation of people from culturally and linguistically diverse communities also varies across administrative datasets. As at 31 December 2022, the NDIA reported that 9.2 per cent of NDIS participants are from culturally and linguistically diverse backgrounds (excluding First Nations people).[137] This is fewer than expected, given that people from culturally and linguistically diverse backgrounds make up 19 per cent of the Australian community.[138]

Additional analysis on culturally and linguistically diverse (CALD) participants published by the NDIA in its September 2021 quarterly report indicated:

> it is likely CALD participants are joining the NDIS but have not been identified as CALD in the data collected, rather than a large number of CALD people with disability not currently being in the NDIS.[139]

The NDIA told us:

> The CALD Strategy is the NDIA's public commitment to work alongside people with disability from CALD backgrounds to ensure they achieve access to, and outcomes from the NDIS on an equal basis with the broader population.[140]

The NDIA said it had identified barriers to people with disability from culturally and linguistically diverse backgrounds accessing the NDIS and using NDIS-funded supports and services. These barriers include the cultural competency of the NDIA and its NDIS partners.[141]

The AIHW told us understandings of disability vary across different culturally and linguistically diverse communities:

> People from different cultural backgrounds can have a different understanding of the concept of disability and this may be reflected in the supports and payments they seek and access.
>
> …
>
> Where people from First Nation communities and CALD backgrounds do access such services, language and cultural differences may result in substantial differences in the extent and way questions are comprehended and understood and in answers provided on disability status and other data items.[142]

These issues mean data on culturally and linguistically diverse people with disability is limited.

LGBTIQA+ people with disability

The AIHW states 'there is very limited data about the intersection of LGBTIQ+ and disability in regular data collections, including in national surveys'.[143] This is consistent with the problems we have encountered in using such data to understand the experience of people with disability from LGBTIQA+ communities.

Research prepared for the Royal Commission also indicated that information is limited:

> To date, the evidence base relating to the health and wellbeing of LGBTIQ+ people with disability in Australia has been limited because larger population-level studies, as well as disability-specific studies, have not included adequate questions about sex, gender and sexuality. The Australian Census does not allow for an accurate estimate of LGBTQA+ population size or an assessment of other health and wellbeing measures for these communities.[144]

Data gaps reduce the capacity to develop evidence-based policy for people with disability from LGBTIQA+ communities. For example, in Public hearing 9, 'Pathways and barriers to open employment for people with disability', Mr Daniel Comensoli, Policy and Research Co-ordinator at the National LGBTI Health Alliance, said inadequate data collection on LGBTIQA+ communities perpetuates the 'invisibility' in data and policy of people with disability who identify as LGBTIQA+:

> the Alliance is really calling for a more LGBTI-inclusive data collection practices because [there] are currently inadequate data collection practices, they perpetuate this cycle of invisibility, and (unclear) evidence-based policy, this exclusion of LGBTI

> people with disability can actually lead to adverse public policy outcomes that fail to address the unique needs and experiences of LGBTI people with disability.
>
> Just finally, I think as articulated in our submission that we provided, I think together with an LGBTI-inclusive ABS survey and census, that will really help build a better picture of LGBTI people with disability in Australia, including their employment outcomes, and it will just help us understand the intersectional needs of LGBTI people with disability more fully in the workplace.[145]

We welcome the intention expressed by the Australian Bureau of Statistics and NDIA to include the new variables for sex, gender, sex characteristics and sexual orientation in their data, including in the *SDAC.*[146] Results from the 2022 *SDAC* are expected to be released in 2024.[147]

Inclusive data collection

We understand the development of the National Disability Data Asset (NDDA) (see Recommendation 12.8) could improve the ability to disaggregate data over time. The Department of Social Services described how this relates to the Outcomes Framework underpinning the ADS:

> As the NDDA is progressively built, reporting is expected to improve data disaggregation for the [ADS] Outcomes Framework. To disaggregate data, the NDDA needs the underlying data to have this built in and the different cohorts mapped consistently across the linked data. Once linked data is in the NDDA, governments will be able to work on improving any issues that affect accurate disaggregation … When developing new data sources for future measures, the ability to disaggregate the data in as many ways as possible will be a priority.[148]

While this work is underway, we need strategies to address data gaps for hard-to-reach and at-risk groups of people with disability. This could involve both improving existing collections and developing new targeted collections. This should occur as part of the Australia’s Disability Strategy 2021–2031 Data Improvement Plan.

It may also be necessary to create new collections for particular cohorts, similar to a personal safety survey focused on First Nations peoples announced in the 2021–22 Budget.[149] For this survey, the Australian Bureau of Statistics is considering ‘issues such as the importance of co-design, awareness of cultural protocols, respondents’ safety, appropriateness as well as conceptual and practical challenges’.[150] These issues should be considered when creating any new collection for all groups of people with disability who experience intersecting and multiple disadvantage.

Recommendation 12.7

The Australian Government and state and territory governments should support a strategy, led by the Australian Bureau of Statistics and the Australian Institute of Health and Welfare, to extend disability data collection:

a. to include people with disability in closed and segregated settings and those with communication support needs

b. to improve data on types of impairment

c. to improve data for intersectional analysis by enhancing data on women with disability; children and young people with disability; and First Nations, culturally and linguistically diverse, and LGBTIQA+ people with disability.

This strategy should form part of the Australia's Disability Strategy 2021–2031 Data Improvement Plan.

2.6. Tracking population outcomes

Multiple governments and agencies in Australia hold data about the interactions of people with disability with services such as education, health and disability. Data linkage connects deidentified data across datasets to tell a 'much more powerful story than is possible from individual data sources in isolation'.[151]

The AIHW told us how data linkage can help resolve data gaps:

> increasingly, data gaps are being filled by creating new linked data sets. Data linkage can also provide powerful new insights into the different pathways and outcomes achieved for people using services without adding collection burden. This means that AIHW can help resolve priority data gaps by creating required data through data linkage after the service delivery event (e.g., through linking data about juvenile justice and National Disability Insurance Scheme (NDIS) participant status).[152]

Data linkage enables longitudinal analysis, which tracks changes over a period of time. Longitudinal analysis can assist with understanding trends and building a policy evidence base for inclusive service and system design. This type of analysis is essential to understanding the outcomes in life for people with disability, as well as the impacts of violence, abuse, neglect and exploitation. For example, in research commissioned by the Royal Commission, Taylor Fry told us:

> Understanding poor outcomes is easier with high-quality longitudinal data, so that changes in outcomes over the life course can be better understood. Combining this with data linkage, creating a combined view across services, will similarly improve our understanding of maltreatment and disadvantage. For instance, it can be used

> to understand how children experiencing abuse [who are] identifiable in the child protection system experience poorer outcomes across health, justice and employment in adulthood.[153]

Taylor Fry also identified a data gap in relation to the systemic neglect of people with disability.[154] Linked data may help to identify where people fall between systems.

Barriers to sharing and linking data

Legislative barriers

The requirement for public sector data to comply with privacy, confidentiality and secrecy laws can also create barriers to sharing public sector data across agencies.[155] In its 2017 report on *Data Availability and Use,* the Productivity Commission identified several features of the *Privacy Act 1988* (Cth) 'that cause uncertainty and may characterise its limited application in a highly data-driven future'.[156]

Further, in its report, the Productivity Commission said:

> State legislation is based on similar principles to the Commonwealth Privacy Act, but the existence of multiple regulatory schemes severely impedes data sharing by the public sector across jurisdictions.[157]

The grey areas between freedom of information, privacy and data sharing laws – as well as the complexities of consent, including what constitutes consent and whether it is reasonable to place the burden on individuals to read long privacy policies – are additional barriers.[158] The Productivity Commission found these complexities can lead to risk aversion, such that 'many areas of Australia's public sector continue to exhibit a reluctance to share or release data'.[159]

To address some of these challenges, the *Data Availability and Transparency Act 2022* (Cth) was introduced to improve the availability and use of public sector data.[160]

Further, the Intergovernmental Agreement on Data Sharing came into effect on 9 July 2021.[161] One of its objectives is to commit 'all governments to use best endeavours to share data between jurisdictions as a default position; where it can be done securely, safely, lawfully and ethically'.[162] The Australian Government and state and territory governments have agreed to 'identify and remove restrictions unnecessarily impeding lawful data sharing, including potential regulatory and administrative barriers'.[163] We welcome these arrangements and expect implementation of the Intergovernmental Agreement will support better sharing of data about people with disability.

Technical barriers

There are technical barriers to establishing safe, secure environments for data linkage and analysis and matching data across systems. In Public hearing 11, 'The experiences of people with cognitive disability in the criminal justice system', Ms Cheryl Axleby, CEO of the Aboriginal Legal Rights Movement in South Australia, said:

> [there] are very complex data systems across governments in each state and territory that do things very differently, there is a lot of inconsistent data, so trying to match that data up, I understand would be a bit of a problem.[164]

There are additional challenges in establishing safe and secure technical environments to enable data sharing, linkage and storage. The Royal Commission into Victoria's Mental Health System recommended information technology be designed to better facilitate data sharing.[165]

Agencies, including the AIHW and the Australian Bureau of Statistics, have introduced technical innovations to enable data linkage and analysis. For example, the Australian Bureau of Statistics established the Multi-Agency Data Integration Project (MADIP) in 2015 following a review of government arrangements for data integration. The MADIP is a secure data asset established to develop a more comprehensive picture of the population. It combines information on health, education, government payments, income and taxation, employment and population demographics (including the *Census*) over time.[166] This enables detailed, deidentified data to be combined for the purpose of answering specific research or policy questions for approved projects.

We understand disability-related projects have or are being conducted using the MADIP including:

- AIHW analysis to understand the use of Medicare Benefits Schedule services and income support payments by people with disability and their carers[167]
- Australian Bureau of Statistics and NDIA work to link NDIS data to the MADIP[168] In its 2017 report on NDIS costs, the Productivity Commission noted the benefits of allowing researchers to have access to individual-level deidentified NDIS data[169]
- Department of Social Services research on labour force participation of people with disability to support the Disability Employment Strategy.[170]

We welcome these projects. However, more can be done to improve the use of data linkage.

2.7. The National Disability Data Asset

Developing the National Disability Data Asset

The National Disability Data Asset (NDDA) is being developed to use data more effectively to understand the experiences of people with disability. The NDDA is a critical step for disability data in Australia. It will help the shift away from disconnected data, organised around government agencies and services,[171] to create a more complete picture of the life experiences of people with disability.[172]

In April 2020, the Australian Government established the NDDA pilot project to examine how to link disability data while respecting people's privacy. It also looked at how to improve the use of data and identify where better data is required.[173]

The NDDA pilot tested the feasibility of creating an enduring national asset comprising linked, deidentified data from government services and agencies across Australia.[174] The pilot tested data linkage in five case studies. It examined early childhood supports, the justice system, pathways from education to employment, disability and mental health and housing.[175]

The AIHW told us:

> Based on the findings of pilot testing to date, the availability of linked data for disability-related purposes would be substantially improved across many policy areas by the implementation of an enduring National Disability Data Asset (NDDA).[176]

Targeted stakeholder engagement with the disability sector and people with disability suggested the NDDA:[177]

- can deliver better data on the experiences of people with disability to inform decision making
- needs to ensure the use of data directly benefits people with disability
- needs to meaningfully engage with people with disability.

In December 2021, the Australian Government committed $40 million over four years to extend the NDDA.[178] On 13 December 2022, disability reform ministers:

> agreed in-principle to progress a Memorandum of Understanding in early 2023 to support governance of the National Disability Data Asset noting individual funding arrangements are subject to bilateral negotiation. Ministers discussed the need to progress resolution of a NDIS Reserve Fund as a potential funding source for jurisdictions that had unspent contributions as at 30 June 2019. Ministers agreed the importance of evidence and data in support for people with disability to strengthen outcomes.[179]

The NSW Government told the Royal Commission about the NDDA as part of the NSW Government Data Strategy:

> The NSW Government is undertaking significant data reform to improve the way data is used and shared. This includes developing the NSW Government Data Strategy, which will grow NSW's maturity in the use of data for better community outcomes. The Strategy highlights the work being done to establish a National Disability Data Asset as a practical case example of how NSW is improving data collection and use …[180]

The Victorian Government similarly demonstrated support:

> The NDDA will enable data insights into how the NDIS interfaces with Victorian mainstream services and other intersecting portfolios, as well as the contribution of the NDIS itself to outcomes for people with disability.[181]

The Department of Social Services has assumed responsibility for establishing the NDDA beyond the life of the pilot project, in partnership with the Australian Bureau of Statistics and AIHW.[182]

The Australian Bureau of Statistics and AIHW are responsible for creating the underlying architecture for an enduring NDDA, known as the Australian National Data Integration Infrastructure (ANDII). This includes designing a new data integration system, the national data linkage model and the design of centralised data products. It also comprises the development of robust data governance, privacy and ethics frameworks.[183] The ANDII architecture has the potential to be used for other national data assets in the future.[184]

In response to questions from the Royal Commission, the Department of Social Services advised that the initial national priorities for centrally coordinated analysis are:[185]

- reporting obligations for the Australia's Disability Strategy Outcomes Framework
- health outcomes for people with disability
- employment outcomes for people with disability.

The Department of Social Services also stated that the NDDA will include data on:[186]

- health and mental health
- early childhood development
- child protection and family support
- school education
- higher education, and vocational education and training
- employment, income and welfare
- housing and community infrastructure
- transport
- justice
- aged care and NDIS supports.

We see significant value in the NDDA's work to address many of the barriers to data linkage and to improving data about people with disability.

Establishing the NDDA as a national resource

We endorse the strategic approach of the NDDA to help foster evidence-based policy making and service design.

Long-term funding commitment by all governments

We acknowledge the importance of the Australian Government's commitment of $40 million to extend the NDDA.[187] However, it is important to guarantee the long-term future of the NDDA and that all Australian governments make a commitment to that effect. Funding by all Australian governments should reflect the importance of the NDDA as a tool for evidence-based policy making and service design across all areas affecting the health, safety and wellbeing of people with disability.

A large-scale, linked data asset requires robust technical architecture, developed with appropriate expertise. Funding should adequately reflect the required investment in technical capabilities and the potential of the ANDII architecture to be used for other purposes.

Governance arrangements

We expect the Department of Social Services, the Australian Bureau of Statistics and AIHW will continue to be responsible for the NDDA.

People with disability should continue to be involved in its co-design, guiding priorities for analysis and advising on the most important datasets for inclusion in the NDDA.

Publishing an annual statistical summary

We propose the Australian Government and state and territory governments, through the Disability Reform Ministerial Council, agree to publish an annual summary of results of analyses conducted using the NDDA. This publication should focus on new insights available from data linkage and longitudinal analysis. We suggest the AIHW should publish the summary alongside its existing reports on the *People with disability in Australia* report and on Australia's Disability Strategy.

The annual statistical summary should be available as a dashboard, using open-source data so the data can be publicly interrogated and used for research. Users should be able to interact with the dashboard and data, so they can perform the analysis they require. All data should be split into smaller components, or 'disaggregated', as far as possible to enable analysis on groups with intersecting and multiple disadvantage.

The dashboard should be highly accessible to all people with disability. It should meet current Web Content Accessibility Guidelines (WCAG) 2.0 Level AA. The Royal Commission supports the AIHW's collaboration with Vision Australia and its digital accessibility specialist agency, Digital Access.[188]

Annual summaries will improve the transparency of the analyses performed using the NDDA. Publication of the analyses and of relevant data projects underway will help ensure that the NDDA provides benefit to people with disability.

Conducting analysis of the NDDA data

We have identified three key evidence gaps in the existing data. We recommend the Australian Government and state and territory governments agree to provide data to the NDDA to address these gaps.

The first gap we have identified concerns factors that place people with disability at greatest risk of violence, abuse, neglect or exploitation. This requires reliable data on the factors that place people with disability at greatest risk of violence, abuse, neglect and exploitation (such as closed and segregated settings); the characteristics of perpetrators of violence, abuse and exploitation; and systemic issues exposing people with disability to the risk of harm, including harm resulting from neglect.[189] The Department of Social Services told us this work could be undertaken through the NDDA:

> Assuming the appropriate data is added to the NDDA, there are resources to fund research and the use is in line with the future NDDA Charter and ethical requirements it could be possible to identify groups of people with disability who may be at high risk of violence, abuse, neglect and exploitation.[190]

The second gap relates to the outcomes and experiences of people with disability transitioning between systems. Research commissioned by the Royal Commission identified the need to understand how people with disability move through service systems.[191] This includes transitioning between education and employment, child protection and justice, and housing and health systems. It is also important to understand the intersection between the NDIS and mainstream services.

The success of the NDDA's pilot projects[192] suggests that this analysis is possible at a national level.

The third gap is the need to evaluate the accuracy of data concerning disability status in various settings. The NDDA pilot demonstrated the NDDA can be used to identify a person with disability in a particular setting, even though they have not been identified as a person with disability in other settings. Information of this kind will help determine priorities for improving the quality and reliability of data relating to disability status.[193]

These measures will improve the evidence base to track the outcomes and experiences of people with disability, and the key risk factors for violence, abuse, neglect and exploitation.

Recommendation 12.8

The Australian Government and state and territory governments, through the Disability Reform Ministerial Council, should commit to long-term support to the National Disability Data Asset (NDDA).

All governments should:

a. by June 2024, commit to continuing funding to establish the NDDA as a national resource for longitudinal analysis of linked data across service systems

b. commit to publishing an annual statistical summary of the analyses of the NDDA's linked data. This should focus on data insights not available from other sources and provide transparency on projects underway. All reported data should be disaggregated as far as possible to enable intersectional analysis.

c. by December 2024, commence specific data projects using the NDDA that:

- identify the factors that put people with disability at greatest risk of violence, abuse, neglect or exploitation
- demonstrate the outcomes and experiences of people with disability transitioning between systems, including:
    - education and employment, child protection and justice systems, and housing and health
    - the NDIS and mainstream services
- evaluate the accuracy of disability status collection in various service settings.

2.8. Current state of disability research

Strategies to extend and improve the collection of disability data will help in monitoring and reporting on outcomes for people with disability. They will also contribute to a more robust evidence base for conducting research.

Recognising the need to build the evidence base for inquiring into violence against, and abuse, neglect and exploitation of, people with disability, we conducted an extensive research program. The Royal Commission's 'A Flourishing Future' research agenda had two main aims:[194]

- to build an evidence base of applied research to support all areas of the Royal Commission's work, in particular to inform the final report recommendations
- to contribute a legacy of information to the research community and fill gaps in the evidence base for advocates, governments, service providers and other organisations.

From the research we commissioned, and from what we heard during public hearings and in submissions and responses to issues papers, it is clear that many research gaps remain. We need more research that examines how to effectively promote social inclusion across various domains to prevent violence against, and abuse, neglect and exploitation of, people with disability. Such research would help Australian governments and service providers adopt more effective ways to design systems and services so people with disability are at the centre. More targeted research would also support the fulfilment of our recommendations and build knowledge to shape future interventions and services.

A full list of our research projects is provided in Volume 2, *About the Royal Commission*, at Appendix G.

The National Disability Research Partnership

The National Disability Research Partnership (NDRP) is the primary vehicle for developing a more coordinated approach to funding and undertaking disability research in Australia. The Australian Government established the NDRP in 2019 as a key initiative under the ADS. The NDRP aims to:

> facilitate a collaborative, translational research program through partnerships between academics, people with disability, their families and carers, peak advocacy and consumer groups, governments and service providers to conduct cutting-edge policy-relevant research that enables people with disability to participate fully in society.[195]

Once fully established, the NDRP will be Australia's independent national research and knowledge hub for the disability sector.[196] Its role includes guiding Australia's investment in disability research. The NDRP research agenda informs how it will allocate research funding over a 10-year period.[197]

In December 2022, the NDRP released its preliminary research agenda, which is broadly designed to:[198]

- advance Australia's capacity to meet its obligations as a signatory to the *CRPD*
- align with major policies such as the ADS and with other research agendas
- encourage research focused on disability policy and practice
- be flexible in responding to emerging priorities while staying focused on longterm, bigpicture priorities.

The NDRP's preliminary research agenda is likely to be updated and finalised in June 2023. The agenda will directly support ADS priorities and will contain research questions aligned to its seven outcome areas:[199]

- employment and financial security
- inclusive homes and communities
- safety, rights and justice
- personal and community support
- education and learning
- health and wellbeing
- community attitudes.

We know further research is needed to deepen the understanding of the diverse experiences of people with disability. We support the ongoing funding of the NDRP as a way of facilitating an inclusive disability research program, addressing research gaps, and collaboratively building evidence for successful policy and research in Australia.

The NDRP recognises it will need to consider the Royal Commission's findings and the research gaps we have identified.[200] In its preliminary research agenda, the NDRP notes:

> We anticipate that the recommendations of the Disability Royal Commission will have implications for the NDRP research agenda in the next few years.[201]

The role of the National Disability Commission

We recognise the challenges in translating complex research into practical knowledge that is able to inform policy and practice. A national approach is needed to analyse program outcomes and undertake research to build a stronger evidence base for services.

In Volume 5, *Governing for inclusion*, we recommend establishing an independent statutory body, the National Disability Commission, to monitor and report on outcomes for people with disability.

We also recommend that the National Disability Commission should play an important role in promoting research. It would collect and disseminate research and information on best practice models and innovative projects and services. Results can be used to improve the quality, effectiveness and inclusivity of disability supports and services. The National Disability Commission should work with the NDRP and with the NDIS (as discussed in Volume 5, *Governing for inclusion*) to ensure the coordination of research approaches where possible.

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3. Our impact

Key points

- A royal commission can prompt significant changes to legislation, policies and community attitudes during its life.
- During this inquiry, the Royal Commission has brought about changes that will improve the lives of people with disability in Australia.
- We recognise our work was not conducted in isolation, but built on the long-term advocacy of people with disability and their supporters to improve the lives of people with disability.
- This chapter identifies the key impacts the Royal Commission had on policy, programs and services during the course of our inquiry.
- These impacts cover a wide range of areas, including:
  - improved access to COVID-19 vaccinations
  - changes to education policies on suspension and exclusion of students with disability
  - a review of the performance of Disability Employment Services providers
  - initiatives to improve the health care of people with cognitive disability
  - measures to tackle violence against women and girls with disability.

3.1. Introduction

For more than four years, the Royal Commission examined in detail the violence, abuse, neglect and exploitation experienced by people with disability in Australia. As set out in Volume 2, *About the Royal Commission*, we held 32 public hearings plus two ceremonial sittings, published 15 final Commissioners' reports on our public hearings and released our *Interim report* summarising the key themes that emerged in the first part of our inquiry.

We have published Commissioners' reports of our public hearings that made findings that governments, regulatory bodies, service providers or individuals failed to protect people with disability from violence, abuse, neglect or exploitation. In some cases, we found that individuals, service providers or other entities with responsibility to care for or support people with disability were directly responsible for perpetrating violence or abuse against, or grievously neglecting the safety and wellbeing of, people with disability.

The evidence given at public hearings; the findings and recommendations in Commissioners' reports on those hearings; and the many other public activities of the Royal Commission have encouraged governments, regulatory agencies, service providers, businesses and others to address the issues we have identified. This has led to significant improvements in policies, programs and practices designed to protect people with disability from violence, abuse, neglect and exploitation, and to promote a more inclusive society.

We recognise our work was not conducted in isolation, but was built on the long-term advocacy of people with disability and their supporters to improve the lives of people with disability. Many of the issues referred to in this report have a history of decades of advocacy by people with disability.

3.2. Responding to COVID-19

As the COVID-19 pandemic escalated during 2020 and 2021, the Royal Commission urged governments, businesses and the community to take swift and effective action to protect people with disability. We sought responses to our concerns about the timely access of people with disability to information, health care and vaccinations, as well as to essential services, food and nutrition. The Royal Commission acted as a communication channel between people with disability and governments to ensure people with disability were not left behind.

A timeline showing the Royal Commission's actions and others' responses is set out in Box 12.1.

In the following sections we summarise the Royal Commission's two public hearings held during 2020 and 2021 to address significant concerns about how governments responded to people with disability during the pandemic.

Box 12.1: Timeline of actions related to the COVID-19 pandemic

- March 2020 – Royal Commission Statement of concern – The response to the COVID-19 pandemic for people with disability
- April 2020 – *Emergency planning and response issues paper*
- August 2020 – Public hearing 5, 'Experiences of people with disability during the ongoing COVID-19 pandemic'
- November 2020 – *Report of Public hearing 5: Experiences of people with disability during the ongoing COVID-19 pandemic*
- April 2021 – Australian Government response to *Report on Public hearing 5: Experiences of people with disability during the ongoing COVID-19 pandemic*

- May 2021 – Public hearing 12, ‘The experiences of people with disability, in the context of the Australian Government’s approach to the COVID-19 vaccine rollout’
- September 2021 – *Public hearing 12: The experiences of people with disability, in the context of the Australian Government’s approach to the COVID-19 vaccine rollout – Commissioners’ draft report*
- October 2021 – *Report of Public hearing 12: The experiences of people with disability, in the context of the Australian Government’s approach to the COVID-19 vaccine rollout*
- October 2021 – *Australian Government response to Public hearing 12: The experiences of people with disability, in the context of the Australian Government’s approach to the COVID-19 vaccine rollout*
- February 2022 – Royal Commission Statement of ongoing concern – The impact of and responses to the Omicron wave of the COVID-19 pandemic for people with disability
- March 2022 – *The impact of and responses to the Omicron wave of the COVID-19 pandemic for people with disability issues paper*
- September 2022 – *Overview of responses to the Impact of and responses to the Omicron wave of the COVID-19 pandemic for people with disability issues paper.*

Public hearing 5

Public hearing 5, ‘Experiences of people with disability during the ongoing COVID-19 pandemic’, was held from 18 to 21 August 2020. It identified serious systemic issues in how government responded to people with disability, especially during the first few months of the pandemic. The Chair stated at the outset that the Commissioners did not intend to wait until the release of the Royal Commission’s *Final report* to make findings and recommendations. The Commissioners considered the Royal Commission had a responsibility to people with disability to prepare a report on the continuing emergency as soon as practicable.[1]

The *Report of Public hearing 5: Experiences of people with disability during the ongoing COVID-19 pandemic* was tabled in the Australian Parliament in November 2020.[2] It was the first Royal Commission report to make both findings and recommendations. The findings and recommendations dealt with the Australian Government’s planning and implementation of its response to the COVID-19 pandemic.

The Australian Government supported, or supported in principle, 21 of our 22 recommendations. It noted the remaining recommendation.[3]

The Australian Government stated its commitment to ongoing engagement with people with disability and their representative organisations in planning for and responding to future emergencies.[4] It listed several initiatives introduced to improve collaboration and consultation both within government and between government and civil society.[5]

Public hearing 12

Public hearing 12, 'The experiences of people with disability, in the context of the Australian Government's approach to the COVID-19 vaccine rollout', was held on 17 May 2021. It followed widespread reports about the slow pace of the vaccine rollout for people with disability and for disability care workers. People also reported a lack of accessible information about the rollout for people with disability, particularly those in residential care settings.

The Commissioners' draft report, *Public hearing 12: The experiences of people with disability, in the context of the Australian Government's approach to the COVID-19 vaccine rollout* was released in September 2021.[6] One of the main reasons the Commissioners decided to publish the draft report was to draw the proposed findings and recommendations to the attention of the Australian Government, state and territory governments, the disability community and the wider Australian community as soon as possible.[7] This was crucial given the rapidly changing situation people with disability faced due to plans to ease COVID-19 restrictions.

The Commissioners' final report was released in October 2021. The Commissioners found the Australian Government's conduct of the vaccine rollout was 'seriously deficient'.[8]

The report identified three core problems with the rollout of vaccines to people with disability, especially people living in disability residential settings:[9]

- a failure to seek advice and guidance from people with disability, disability support workers, disability representative organisations and service providers at critical points in the development and implementation of the COVID-19 Vaccine Rollout Strategy
- a lack of transparency in decision-making, denying people with disability the information they were entitled to receive. In particular, this included the failure to reveal the decision to deprioritise people with disability who had originally been covered in Phase 1A of the Rollout Strategy
- a failure to provide information in an accessible form to people with disability who were at risk of serious consequences if they became infected with the virus.

The report made seven recommendations to ensure people with disability and disability support workers had the opportunity to be vaccinated before COVID-19 restrictions were eased by governments.[10]

The Australian Government accepted six of the seven recommendations.[11] It noted the recommendation concerning easing of restrictions in line with vaccination thresholds being reached, noting this was the responsibility of state and territory governments. The Australian

Government said it would approach the recommendations ‘as important pointers to supporting Australians with disability to access and rely on the protection of a COVID-19 vaccine’.[12]

On 13 October 2021, the Australian Department of Health and Aged Care issued a statement advising it was prioritising the needs of people with disability in the vaccine rollout.[13] It also updated the list of Australian Government COVID-19 vaccination services for people with disability, family members, carers and disability workers.[14]

3.3. Impacts on disability policy, programs and services

Community attitudes to people with disability

Disability inclusion training

In March 2022, the then Minister for Families and Social Services, Senator the Honourable Anne Ruston, announced funding for disability inclusion training. She noted evidence provided to the Royal Commission’s public hearings ‘highlighted the need for consolidated training to increase disability inclusion’.[15]

The Australian Council of Learned Academies received $1 million under the ADS to design the project and shape the higher education curriculum to include disability confidence training.[16] A report on the project, released in late 2022, proposed that training should be multi-faceted, and set out key principles and actions for improving understanding of disability inclusion across occupations.[17]

Disability services

Actions in response to Public hearing 13 findings and recommendations

From 24 to 28 May 2021, the Royal Commission held Public hearing 13, ‘Preventing and responding to violence, abuse, neglect and exploitation in disability services (a case study)’. It examined the experiences of three people with disability, ‘Melissa’, ‘Carl’ and ‘Chen’[18] living in a single residential disability setting in Western Sydney, operated by the service provider, Sunnyfield Disability Services (Sunnyfield). They were abused at the residence by two employees of Sunnyfield.[19]

In April 2022, the Royal Commission *Report of Public hearing 13: Preventing and responding to violence, abuse, neglect and exploitation in disability services (a case study)* recommended the Chief Executive Officer (CEO), Ms Caroline Cuddihy, and appropriate members of the Board of Sunnyfield should meet with Melissa, Carl and Chen, or their families, to:[20]

- apologise for Sunnyfield’s failures to prevent the violence and abuse they endured
- discuss what redress and/or additional supports and assistance they require.

In Public hearing 32, 'Service providers revisited', Mr Andrew Hyland, CEO of Sunnyfield, told the Royal Commission Melissa, Carl, Chen and their families had received letters of apology from the CEO, and the Chair of the Board met with the families to apologise.[21] Mr Hyland also said, in response to the Royal Commission's findings and recommendations, Sunnyfield had implemented changes to recruitment practices, oversight by regional managers, training for house managers, and protocols for communication between service coordinators and families.[22]

Actions in response to Public hearing 20 recommendations

In Public hearing 20, 'Preventing and responding to violence, abuse, neglect and exploitation in disability services (two case studies)', the Royal Commission examined the experiences of two groups of people with disability living in supported accommodation operated by non-government service provider Life Without Barriers (LWB) in Lismore and Melbourne.[23] In a report released on 28 February 2023, Commissioners made six recommendations:[24]

- Recommendation 1: LWB should review its policies, procedures and training to better equip staff to support clients in having intimate relationships, and to codesign amendments to policies, procedures and training documents with clients.
- Recommendation 2: LWB should review its personal care policies to provide clear guidance to staff about how rostering decisions should accommodate personal care preferences, and to guide staff responses if this is not possible.
- Recommendation 3: LWB should provide further information to the Royal Commission about its progress towards improving record keeping and incident reporting, particularly regarding client medical records.
- Recommendation 4: LWB should amend the Vacancy Management Policy to require consultation with existing clients and their families before any decision is made to accept a new resident into a group home.
- Recommendation 5: LWB should promptly date all policies and make them readily available to affected residents, their families and staff.
- Recommendation 6: LWB should consider making an ex gratia payment to 'Natalie'[25] as compensation for the conduct of LWB 'Worker 3'.[26]

Before Public hearing 32, LWB also provided a written report on progress with respect to changes and improvements in policies and practices since Public hearing 20.[27] The report included information about improved record keeping and incident reporting (Recommendation 3).[28]

In Public hearing 32, Ms Claire Robbs, CEO of LWB, gave evidence that in response to recommendation 1, LWB expected to develop a new policy position on intimate relationships by mid-2023. In the interim, LWB had delivered training and other guidance to disability support workers and front-line leaders.[29]

In response to recommendation 2, Ms Robbs indicated LWB had reviewed its personal care policies and described the steps to be taken if a client's preferences could not be met.[30] Ms Robbs also noted, in response to recommendation 4, LWB had reviewed its vacancy management policy and implemented the amended policy across the organisation.[31] In relation to recommendation 6, Ms Robbs said an offer of compensation had been made to Natalie, but not of a specific sum.

Actions in response to Public hearing 23 findings

In Public hearing 23, 'Preventing and responding to violence, abuse, neglect and exploitation in disability services (a case study)', held in May 2022, the Royal Commission examined the experiences of three young people with disability who participated in a day program operated by Afford in Mt Druitt, New South Wales.[32] Commissioners made 29 findings about Afford's response to abuse perpetrated by an employee and the organisational environment in which the abuse occurred.[33]

In Public hearing 32, Ms Joanne Toohey, CEO of Afford, gave evidence that, since Public hearing 23, Afford had implemented:

- a new learning and development strategy, supported by a new learning and development matrix
- new incident management policies and procedures.[34]

Ms Toohey described changes made within the organisation to improve staff retention, including greater use of permanent rather than casual employment and a new reward and recognition program.[35]

Afford also underwent a review of its constitution.[36] The new constitution provides Afford must have at least six and no more than 10 directors, and at least one of the directors must be a person with disability.[37] In line with this constitutional requirement, at the time of Public hearing 32, Afford had recruited two new board members who are people with disability.[38]

Following Public hearing 32, Afford told the Royal Commission that it 'acknowledges and accepts full responsibility for its failures in governance identified by the Royal Commission' and accepts that it must be held accountable. It reported that three board directors, including the chairman, Mike Allen, had resigned with immediate effect on 19 February 2023.[39]

Disability strategies

Australia's Disability Strategy

In December 2021 the Australian Government launched *Australia's Disability Strategy 2021–2031* (ADS), which built on its predecessor, the *National Disability Strategy 2010–2020*. The ADS states:

> The Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability and the work of the Commission has also shaped the development of this Strategy and will shape future updates to the Strategy. Governments are committed to reviewing the Strategy upon the release of the Commission's final report.[40]

The ADS includes targeted action plans that apply an intensive focus to achieve specific deliverables and outcomes for people with disability. In November 2022, at Australia's Disability Strategy Forum, the Minister for Social Services, the Honourable Amanda Rishworth MP, said the Royal Commission's final report will inform the next set of targeted action plans:

> Late next year, following the final Report of the Royal Commission, my department will be reviewing the Strategy. A key focus will be what the next set of Targeted Action Plans should focus on.[41]

State and territory disability plans

Each Australian state and territory is required to develop its own disability strategies to support the delivery of the ADS. Some states and territories launched their new plans during the period of the Royal Commission.

Several of these plans committed to consider our findings and recommendations in implementation and/or future iterations:[42]

- The New South Wales Disability Inclusion Action Plan 2021–2025 states it 'is aligned in intention' with the ADS and the work of Royal Commission.[43]
- Inclusive Victoria: state disability plan (2022–2026) recognises the Royal Commission as part of the national legal and policy framework within which the plan fits.[44]
- Queensland's Disability Plan 2022–2027: Together, a better Queensland [45] was developed following a review of its predecessor. That review identified the importance of aligning with the Royal Commission's findings and recommendations.[46]
- Inclusive SA: State Disability Inclusion Plan 2019–2023 is South Australia's first disability inclusion plan.[47] Its interim review recorded it was safeguarding the rights of people with disability by providing consistent, accurate and relevant information about the Royal Commission.[48]
- A Western Australia for Everyone: State Disability Strategy 2020–2030 will use the Royal Commission's recommendations to further improve the safety of people with disability.[49]
- Northern Territory Disability Strategy 2022–2032, the Northern Territory Government's first disability strategy,[50] and Action Plan[51] was launched in August 2022. The Strategy notes the work of the Royal Commission, including our reporting on the importance of having First Nations member-led organisations to combat 'double discrimination' of Aboriginal people with disability.[52]

Education

We held three public hearings on inclusive education during our inquiry:

- Public hearing 2, ‘Inclusive education in Queensland – preliminary inquiry’ (November 2019)
- Public hearing 7, ‘Barriers experienced by students with disability with accessing and obtaining a safe, quality and inclusive school education and consequent life course impacts’ (May 2021)
- Public hearing 24, ‘The experience of children and young people with disability in different education settings’ (June 2022).

National review of disability standards for education

In March 2021 the Australian Government released the *Final report of the 2020 review of the disability standards for education 2005*. It made 13 recommendations.[53] The review acknowledged it was informed by the work of the Royal Commission[54] and drew on information from our *Interim report* about First Nations people and disability identity.[55] It also drew on evidence presented at Public hearing 2 about how the increase in decision-making authority of school principals has come with an increase in devolved authority.[56] In addition, the review referred to Public hearing 7 about how discretionary power provided to schools and principals often leads to unevenness in inclusive practices and allocation of disability funding.[57]

Education policy in Queensland

In June 2022, the Queensland Government announced a new funding model for students with disability in state schools. Under the funding model, schools will receive $80 million over two years to fund almost 500 new front-line positions. The funding will support schools to transition to a new resourcing model for students with disability as the Education Adjustment Program (EAP) model is phased out.[58] This new funding model responded to a recommendation proposed by Counsel Assisting following Public hearing 7, that Queensland move from the EAP to a non-categorical resourcing model as soon as possible.[59]

Education policy in the Australian Capital Territory

The Australian Capital Territory Government passed the *Education Amendment Act 2022* (ACT) in June 2022. It commenced on 22 December 2022. The Act clarifies when and why schools can expel or suspend students. The Explanatory Statement to the Education Amendment Bill 2022 (ACT) noted the Royal Commission had identified that students with disability were disproportionately suspended and expelled from schools. The statement noted the proposed amendments would address the Royal Commission’s concerns expressed in our *Interim report* about the misuse of disciplinary measures such as suspensions and exclusions.[60]

Employment

The Royal Commission held four public hearings examining disability employment services:

- Public hearing 9, ‘Pathways and barriers to open employment for people with disability’ (March 2021)
- Public hearing 19, ‘Measures taken by employers and regulators to respond to the systemic barriers to open employment for people with disability’ (November 2021 and March 2022)
- Public hearing 21, ‘The experience of people with disability engaging with Disability Employment Services’ (February 2022)
- Public hearing 22, ‘The experience of people with disability working in Australian Disability Enterprises’ (April 2022).

A new national disability employment support model

In August 2022, following the two public hearings on employment services (Public hearings 21 and 22), the Australian Government Department of Social Services released the consultation report, *Inclusive. Accessible. Diverse. Shaping your new disability support program.* The report noted the new Disability Employment Support Model would be informed by a range of initiatives, including the work of the Royal Commission.[61]

Review of Disability Employment Services providers

On 21 August 2022, following a review, the Australian Government announced that around 6 per cent of Disability Employment Service (DES) providers would be discontinued for poor quality and an inability to achieve outcomes. A total of 52 providers were affected, with eight providers having all their services discontinued.[62] The Minister for Social Services, the Honourable Amanda Rishworth MP, stated the review was initiated following evidence given to the Royal Commission. The evidence showed ‘some DES providers were not achieving long-term outcomes, with some job placements ending abruptly or only lasting for the duration of government subsidies’.[63]

Actions in response to Public hearing 21 recommendations

Public hearing 21 examined a case study involving ‘Mzia’[64] who has attention deficit hyperactivity disorder and worked for the DES provider AimBig from June 2019 until January 2020. The Royal Commission’s *Report of Public hearing 21: The experience of people with disability engaging with Disability Employment Services: Mzia case study* made 11 findings about the DES provider and its related companies. The findings included that AimBig failed to provide appropriate support to Mzia after it placed her in its barista training program.[65]

The report also included three recommendations:[66]

- Ms Marcella Romero, the CEO and Managing Director of Arriba Group Pty Ltd, sole Director of AimBig and sole Director of Rehab Management, should make an unqualified apology to Mzia. The apology should acknowledge how and why AimBig failed Mzia as an employee and as a DES participant, and should acknowledge the impact of those failures upon Mzia.
- AimBig should consider making appropriate redress to Mzia for the adverse impact on her health, wellbeing and future employment prospects as a result of AimBig's acts and omissions.
- Arriba Group should review its employment contracts to ensure they refer to the correct laws and correct awards. It should also consider ensuring that its contracts are in plain English, in a form easily understood by an employee or prospective employee with disability.

In January 2023, the media reported that Arriba Group had stated Ms Romero will contact Mzia to make a direct apology.[67]

Family, domestic and sexual violence

Funding to tackle violence against women and girls with disability

Public hearing 17, 'The experience of women and girls with disability with a particular focus on family, domestic and sexual violence', was held from 13 to 14 October 2021 and 28 March 2022 to 1 April 2022.

In its 2021–22 Budget, the Australian Government committed $9.3 million over three years for preventing and responding to violence against women and girls with disability.[68] In its *Women's Budget Statement*, the Australian Government said the funding was a response to the work of the Royal Commission in highlighting the higher levels of violence experienced by women and girls with disability.[69] The funding was to develop resources aimed at driving a reduction in violence against women and girls with disability and improving responses when violence occurs.[70]

National Plan to End Violence Against Women and Children 2022–2032

The National Plan to End Violence Against Women and Children 2022–2032 acknowledged that the work of the Royal Commission would guide its future work towards ending violence against women and children with disability.[71]

Health

The Royal Commission held three public hearings focusing on health care:

- Public hearing 4, ‘Health care and services for people with cognitive disability’ (February 2020)
- Public hearing 6, ‘Psychotropic medication, behaviour support and behaviours of concern’ (September 2020)
- Public hearing 10, ‘Education and training of health professionals in relation to people with cognitive disability’ (December 2020 and March 2021).

Improved health care for people with disability

Public hearing 4, held in February 2020, and Public hearing 6, held in September 2020, informed initiatives to provide safer, quality health care for people with disability, particularly for people with cognitive disability. The Australian Commission on Safety and Quality in Health Care (ACSQHC) committed to undertake further work on the issues the Royal Commission examined in Public hearing 4. Between 2020 and 2022, the ACSQHC announced a number of initiatives, including:

- expanding its cognitive impairment work program[72]
- releasing the Australian Charter for Healthcare Rights in accessible formats for people with cognitive impairment[73]
- working with the NDIS Quality and Safeguards Commission to increase engagement across the health and disability sectors and to identify shared goals in the health care of people with disability.[74]

Australia’s Primary Health Care 10 Year Plan 2022–2032

There has also been a focus on improving access to primary health care services for people with disability. The Australian Government released Future Focused Primary Health Care: Australia’s Primary Health Care 10 year Plan 2022–2032 in March 2022 (Primary Health Care Plan).[75] It builds on major shifts in the health system in response to this Royal Commission, other inquiries (such as the Productivity Commission Inquiry into Mental Health) and the COVID-19 pandemic.[76] The plan has a specific action area on ‘improved access to appropriate care for people at risk of poorer health outcomes’, which includes people with disability.[77] It includes a commitment to respond to the Royal Commission’s final report with further primary healthcare reforms.[78]

National Roadmap for Improving the Health of People with Intellectual Disability

The National Roadmap for Improving the Health of People with Intellectual Disability, released in July 2021, forms part of the Australian Government's Primary Health Care Plan. The roadmap specifically states that the issues raised in our health-related hearings have informed its development.[79] The findings and recommendations in our *Final report* will guide its implementation.[80]

Improving services for people with autism

The Senate Select Committee on Autism examined the services, support and life outcomes for people with disability. It delivered its final report, *Services, support and life outcomes for autistic Australians*, in March 2022. It recommended the Australian Government develop a national autism strategy, to be informed by the recommendations of the Royal Commission, along with other considerations.[81] The Australian Government accepted this recommendation.[82]

Autism Aspergers Advocacy Australia (A4) prepared a briefing for health officials, 'Autistics Australians and Health Systems in Australia'. It referred to Public hearing 4 regarding the need to improve health care and services for people with cognitive disability, including autistic people.[83] It also referenced our *Report of Public hearing 10: Education and training of health professionals in relation to people with cognitive disability* recommendations on ways to improve the training of health professionals to better respond to people with cognitive disability.[84]

In August 2022, representatives from the autism community and the Australian Government Department of Health and Aged Care met to discuss the National Autism Strategy and Roadmap. They highlighted that health outcomes for autistic Australians are unsatisfactory and must improve.[85]

In the 2022–23 October Budget, the Australian Government provided $5.3 million over two years from 2022–23 to improve outcomes for people with autism, which included $1 million for the development of the National Autism Strategy.[86]

Inappropriate use of psychotropic medicines

Evidence given at Public hearing 6, 'Psychotropic medication, behaviour support and behaviours of concern', establishes that psychotropic medicines are being over-prescribed to manage behaviours of concern by people with disability.[87] In response, the Aged Care Quality and Safety Commission, the NDIS Quality and Safeguards Commission and the Australian Commission on Safety and Quality in Health Care released a joint statement in March 2022 entitled *Inappropriate Use of Psychotropic Medicines to Manage the Behaviours of People with Disability and Older People*. It recognised the inappropriate use of psychotropic medicines and outlined steps to reduce their misuse.[88] It drew on the work of this Royal Commission along with the findings of the Royal Commission into Aged Care Quality and Safety. It concluded that psychotropic medicines 'are being misused and overused, particularly with older people and people with disability' and that 'inappropriate use of psychotropic medicines has been recognised as a safety and quality issue in health care'.[89]

A National Centre of Excellence in Intellectual Disability Health

Witnesses at Public hearing 4 and Public hearing 10 gave evidence in support of the establishment of a network of centres or a national centre of excellence on intellectual or cognitive disability health.[90]

In April 2022, the Australian Government announced $28 million in funding for the establishment of a National Centre of Excellence in Intellectual Disability Health.[91]

In the 2022–23 October Budget, the Australian Government provided $15.9 million over four years to establish and support the National Centre of Excellence, which:

> will deliver a central hub of expertise, resources and research on the health care of people with intellectual disability and provide leadership in meeting the needs of people with intellectual disability.[92]

Justice

The Royal Commission held three public hearings on the experiences of people with disability in the criminal justice system:

- Public hearing 11, 'The experiences of people with cognitive disability in the criminal justice system' (February 2021)
- Public hearing 15, 'People with cognitive disability and the criminal justice system: NDIS interface' (August 2021)
- Public hearing 27, 'Conditions in detention in the criminal justice system' (September and October 2022).

Western Australian review of the *Young Offenders Act 1994*

On 4 October 2022, the Western Australian Government announced it had instructed the Department of Justice to review the *Young Offenders Act 1994 (WA)*. The review was expected to take 12 months.[93] This announcement occurred during Public hearing 27, which largely focused on conditions in detention in Western Australia.

In January 2023, Human Rights Watch criticised conditions in Western Australian prisons in its annual *World Report 2023*.[94] The Western Australia Corrective Services Minister, the Honourable Bill Johnston MLA, reported the Western Australian Government was actively responding to the Royal Commission and our proposals for change.[95]

Australian Capital Territory Disability Justice Strategy 2019–2029

The Australian Capital Territory Government's Disability Justice Strategy 2019–2029 will provide 'a vehicle' for the government to respond to our final recommendations.[96] In September 2021, the *Disability justice strategy: Second annual progress report* referenced the 'important evidence about people with cognitive disability and the criminal justice system' at Public hearings 11 and 15.[97] It noted our subsequent recommendations would inform future work and drive the Disability Justice Strategy.[98]

Legislation

A new Act to replace the *Disability Services Act 1986* (Cth)

In November 2022, the Australian Government announced a review of the *Disability Services Act 1986* (Cth) to provide a foundation for disability support services outside the NDIS.[99] The review will consider the work of this Royal Commission to ensure input provided by people with disability is used to inform the review.[100]

National Disability Insurance Scheme

Review into the National Disability Insurance Scheme

On 18 October 2022, the Australian Government announced an Independent Review into the National Disability Insurance Scheme (NDIS), which is due to report to the Disability Reform Ministerial Council by October 2023.[101] It will make findings and recommendations for reform and provide a plan for implementation. The terms of reference direct the Review panel to have careful regard to the findings and proceedings of previous and ongoing reviews and inquiries, including this Royal Commission.[102]

Refresh of NDIS Participant Employment Strategy

Following the conclusion of the NDIS Participant Employment Strategy 2019–2022 in December 2022, the NDIA evaluated the progress of the strategy and reviewed priorities for 2023. In its quarterly report to disability ministers in September 2022, the NDIA stated:

> The refresh of the strategy will be timed to ensure alignment with the broader vision of disability employment, and pending recommendations from the Disability Royal Commission (DRC) review into people's experience with Australian Disability Enterprises (ADEs) and DSS planned policy development and review of Disability Employment Services (DES) in 2023.[103]

New NDIS emergency management practice standard

A set of new practice standards and associated quality indicators for NDIS service providers came into effect on 15 November 2021, with a staggered transition period for existing NDIS providers. One of the standards is concerned with improving emergency and disaster management. This standard was developed as a result of evidence presented to the Royal Commission at Public hearing 5, ‘Experiences of people with disability during the ongoing COVID-19 pandemic’ and the experience of the NDIS in supporting providers during the pandemic.[104]

The standard is found in the *National Disability Insurance Scheme (Quality Indicators for NDIS Practice Standards) Guidelines 2018* (Cth).[105]

Transport

In November 2022, the Royal Commission held two workshops focused on the experiences of people with disability using domestic air travel and airports. More than 60 participants attended the workshop sessions, including representatives from various disability representative organisations.[106]

On 3 February 2023, the Chair of the Royal Commission, the Honourable Ronald Sackville AO KC, wrote to the chief executive officers of Australia’s major airlines and domestic airports. The Chair outlined the concerns people with disability have about air travel, including that they frequently faced ‘inaccessible facilities and services’ and ‘unhelpful practices and systems adopted by airlines’.[107]

A statement on behalf of Qantas and Jetstar said the airline group was considering the matters raised by the Chair and is ‘working hard to improve the experience for customers with accessibility needs’.[108] A Virgin Australia spokesperson said it would be giving the Royal Commission’s letter very close consideration, noting ‘how important it is to ensure we make airline travel inclusive and accessible for all our guests’.[109]

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Acronyms and abbreviations

ABS – Australian Bureau of Statistics

ACSQHC – Australian Commission on Safety and Quality in Health Care

ACT – Australian Capital Territory

ADS – Australia’s Disability Strategy 2021–2031

AIHW – Australian Institute for Health and Welfare

AK – Knight of the Order of Australia

ANDII – Australian National Data Integration Infrastructure

AO – Order of Australia

CALD – culturally and linguistically diverse

CEO – Chief Executive Officer

CRPD – Convention on the Rights of Persons with Disabilities

CVO – Commander of the Royal Victorian Order

DES – Disability Employment Service

DSP – Disability Support Pension

DSS – Department of Social Services

EAP – Education Adjustment Program

ICF – International Classification of Functioning, Disability and Health

KC – King’s Counsel

LWB – Life Without Barriers

MADIP – Multi-Agency Data Integration Project

MC – Military Cross

NCCD – Nationally Consistent Collection of Data

NDA – National Disability Agreement

NDDA – National Disability Data Asset

NDIA – National Disability Insurance Agency

NDIS – National Disability Insurance Scheme

NDRP – National Disability Research Partnership

NDS – National Disability Strategy 2010–2020

NSW – New South Wales

PSS – Personal Safety Survey

SA – South Australia

SDAC – Survey of Disability, Ageing and Carers

WA – Western Australia

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