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

First Nations people with disability

Final Report
Volume 9

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Acknowledgement of Country

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

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

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

Acknowledgement of people with disability

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

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

Content warnings

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

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

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

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Key terms

First Nations peoples

The Royal Commission uses the term ‘First Nations peoples’ to denote both the Aboriginal people of mainland Australia, Tasmania and other islands off the continent, and the people of the Torres Strait Islands. This term reflects the social and governance structures and systems in place prior to colonisation.

There are also instances where people we engaged with identified themselves as either ‘Aboriginal’ or ‘Torres Strait Islander’, or they have referred to themselves by reference to their language group, and we have respected their personal choices.

Aboriginal Community Controlled Organisations

An Aboriginal Community Controlled Organisation (ACCO) is an incorporated Aboriginal or Torres Strait Islander organisation that is initiated by, based in and governed by a local First Nations community to deliver holistic, culturally appropriate services to the community that controls it. We also use the term First Nations Community Controlled Organisation throughout this document.

Aboriginal Community Controlled Health Organisations

An Aboriginal Community Controlled Health Organisation (ACCHO) is a primary health care service that is operated by a local Aboriginal community to deliver holistic, comprehensive and culturally appropriate health care to the community that controls it, through a locally elected board of management.[1]

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[1] ‘Aboriginal Community Controlled Health Organisations’, *National Aboriginal Community Controlled Heath Organisation,* web page. <www.naccho.org.au/acchos/>

Summary

Key points

- First Nations people with disability are uniquely marginalised in Australia.
- We heard the voices of First Nations people with disability through our community engagements, public hearings and private sessions, as well as submissions and research.
- The experiences of First Nations people with disability cannot be separated from the ongoing impacts of colonisation, intergenerational trauma and racism experienced by First Nations people more generally.
- This continues in the over-representation of First Nations people with disability in child protection and criminal justice systems, high rates of institutionalisation, child removal and economic exclusion.
- Our work was informed by the human rights of First Nations people with disability, both as a distinct cultural group and as individuals with disability. We were guided by the *Convention on the Rights of Persons with Disabilities* and the United Nations *Declaration on the Rights of Indigenous Peoples.*
- The rights of First Nations people with disability are intrinsically tied to their holistic physical, cultural and spiritual health and wellbeing.
- First Nations cultural understandings of inclusion do not align with Western concepts of disability, particularly the focus on individual impairment over collective wellbeing. Culture, Country, kin and community safeguard First Nations people with disability from violence, abuse, neglect and exploitation.
- The prevalence of disability is much higher in First Nations populations than in the general population. However, First Nations people with disability face barriers to accessing culturally safe and inclusive services across many systems.
- First Nations people with disability also experience significant barriers to accessing and participating in the National Disability Insurance Scheme, which are exacerbated in remote and very remote communities. This constitutes systemic neglect.
- Policy frameworks and service delivery often fail to recognise and respond to the distinct needs of First Nations people with disability. The needs of First Nations people with disability are often overlooked, ignored or forgotten.
- The voices of First Nations people with disability need to be strengthened.

The voices of First Nations people with disability are central to our work. This volume sets out the issues and themes identified through listening to the many stories shared with us by a wide range of First Nations people with disability, their families, carers, supporters and communities. It highlights the challenges they face and proposes changes to prevent violence against, and abuse, neglect and exploitation of, First Nations people with disability.

The ongoing impacts of colonisation on First Nations people are well understood. Its legacy continues today in the over-representation of First Nations people in criminal justice systems, high rates of institutionalisation and child removals, shorter life expectancies, and economic exclusion. As set out below, colonisation itself has been a disabling force.[1] How its ongoing impacts – violence, dispossession and racism – shape the lives of First Nations people with disability is less understood.

First Nations people with disability walk in multiple worlds, navigating Indigenous rights, disability rights and mainstream laws, culture and settings.[2] They have told us they often experience a 'double disadvantage' at the intersection of racism and ableism.[3] Ableism is a form of disability discrimination.

We propose a renewed commitment to address this marginalisation by elevating their needs, aspirations and priorities in policy and programs.

This volume has eight chapters:

- **Chapter 1 – Introduction** presents the human rights framework across the *Convention on the Rights of Persons with Disabilities* (*CRPD*) and the United Nations *Declaration on the Rights of Indigenous Peoples* (*UNDRIP*), as well as the broader historical context and relevant policy frameworks.
- **Chapter 2 – Disability: 'Not a word we use'** describes the different ways in which First Nations communities understand disability, the barriers created by dependency on diagnosis and identification within the medical model of disability, and the potential for inclusion under a cultural model.
- **Chapter 3 – Ensuring cultural safety** looks at the importance of First Nations people with disability having access to First Nations-led, culturally appropriate systems and services.
- **Chapter 4 – The experiences of First Nations people with disability** looks at available data and identifies current gaps in data collection. It also looks at the nature and extent of violence, abuse, neglect and exploitation throughout the life course in the contexts of education, health, and domestic and family violence.
- **Chapter 5 – Child protection** examines what parents and children have told the Royal Commission about their experiences with child protection systems.
- **Chapter 6 – Criminal justice** looks at the experiences of those who come into contact with justice systems as adults, young people and children. The focus is on pathways into contact with criminal justice systems, screening, and the conditions in justice settings.

- **Chapter 7 – The unmet potential of the NDIS for First Nations people with disability** looks at their experiences in relation to the National Disability Insurance Scheme (NDIS), including in remote and very remote areas.
- **Chapter 8 – The case for structural reform** identifies opportunities to strengthen current outcomes for First Nations people with disability through strengthening their voices, improving cultural safety, and building the First Nations disability workforce.

Endnotes

1 Julie King, Mark Brough & Marie Knox, ‘Negotiating disability and colonisation: the lived experience of Indigenous Australians with a disability’, (2013), vol 29 (5), 738–750, *Disability and Society*, pp 739, 743.

2 Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, *Agents of our own destiny: Activism and the road to the Disability Royal Commission*, November 2021, p 19.

3 Lester Bostock, ‘Access and equity for people with a double disadvantage’, (1991), vol 2, *Australian Disability Review*, pp 3–8.

Recommendations

Recommendation 9.1 Culturally appropriate parenting capacity assessments

State and territory governments should work with First Nations child protection services, peak bodies and First Nations people with disability to co-design clear principles and guidelines for parenting capacity assessments for First Nations parents with disability in their jurisdiction, to ensure assessments are culturally appropriate. The principles and guidelines should include:

- best practice standards of cultural competence for practitioners conducting parenting capacity assessments of First Nations parents with disability
- guidance to assist practitioners conducting parenting capacity assessments of First Nations parents with disability to identify and address assessment test errors that may result from an insufficient understanding of how cultural factors affect assessments of parenting capacity
- a requirement that practitioners conducting parenting capacity assessments of First Nations parents with disability complete mandatory training to implement best practice standards of cultural competence, using testing tools that are culturally appropriate and disability appropriate
- establishing a review process to ensure the design and implementation of these standards is consistent across states and territories.

Recommendation 9.2 Ages and Stages Questionnaire-Talking about Raising Aboriginal Kids (ASQ-TRAK)

State and territory governments should ensure all First Nations children up to five years of age coming into out-of-home care are screened using the culturally adapted developmental screening Ages and Stages Questionnaire-Talking about Raising Aboriginal Kids (ASQ-TRAK) tool. Children who are vulnerable in two or more of the five domains of communication, gross motor, fine motor, problem solving, and personal-social should be supported by an application for an Early Childhood Early Intervention plan.

Recommendation 9.3 Cultural safety of First Nations people in criminal justice settings

By the end of 2024, state and territory governments should review the effectiveness of their strategies, if any, directed to providing and ensuring the cultural safety of First Nations people with disability in criminal justice settings and in doing so take into consideration what the Royal Commission has heard about that issue.

The review findings and recommendations should be made public.

Recommendation 9.4 Expand community connector programs

The National Disability Insurance Agency should increase the number and coverage of the community connector programs for First Nations people with disability in remote areas. The implementation of the programs should be community-led and delivered. This expansion must be accompanied by adequate long-term funding for the programs and organisations delivering the programs, with sufficient training for staff delivering the programs.

In regions where English is not the preferred language for First Nations people, the programs should focus on recruiting staff who speak local languages.

Recommendation 9.5 Block funding the community-controlled sector

The National Disability Insurance Agency (NDIA) should provide block funding for First Nations Community Controlled Organisations to flexibly deliver supports and services to First Nations people with disability. This could include funding for:

- respite or accommodation in connection with their plan or disability services
- cultural supports to maintain or improve health and wellbeing
- essential supports such as food, bedding and clothing
- supports that enable access to therapy, such as transport and fuel
- translation or other services to build understanding around disability and the National Disability Insurance Scheme
- other matters as agreed by the NDIA and First Nations Community Controlled Organisations.

Recommendation 9.6 National Disability Insurance Agency Board

Section 127 of the *National Disability Insurance Scheme Act 2013* (Cth) should be amended to provide that the National Disability Insurance Agency Board must include at least one First Nations person at all times.

Recommendation 9.7 Participation in cultural life

Sections 3, 4 and 17A of the *National Disability Insurance Scheme Act 2013* (Cth) should be amended to refer to participation in cultural life, in addition to participation in social and economic life.

Recommendation 9.8 Return to Country

In consultation with the First Nations Advisory Council, the National Disability Insurance Agency (NDIA) should:

- create a new line item in the Pricing Arrangements recognising cultural supports and return to Country trips
- develop guidelines for NDIA staff on including cultural supports and return to Country trips as reasonable and necessary supports in plans
- educate First Nations participants about the availability of cultural supports and return to Country trips included in their plans.

Recommendation 9.9 Criteria for funding family supports

The National Disability Insurance Agency (NDIA), the First Nations Advisory Council and First Nations Community Controlled Organisations should co-design policy guidelines on funding for First Nations family members to provide supports to participants in remote communities. Any policy guidelines should consider:

- the risk of financial exploitation, the need for a regulatory framework and oversight, and whether a similar approach would apply to non-First Nations carers in remote communities in similar situations
- the availability of suitable services, including culturally safe services

- training for NDIA staff on how to apply the policy guidelines, including how staff can support family to apply to be paid for the care provided
- building awareness of the circumstances in which participants and their families can apply to be paid
- how to build the capacity of family and community members to become part of the local workforce, such as trained support or community workers, which may include connecting family members with a First Nations Community Controlled Organisation.

Recommendation 9.10 First Nations Disability Forum

The Australian Government and state and territory governments should support the establishment of a First Nations Disability Forum to lead further development and implementation of the Disability Sector Strengthening Plan (DSSP) by the end of March 2024. The Forum should consist of representatives of:

- First Peoples Disability Network
- First Nations Community Controlled Organisations
- both Aboriginal and Torres Strait Islander peak bodies
- First Nations people with disability.

The Forum should be supported by a First Nations disability investment fund, with the purpose of:

- supporting the operation of, and participation in, the Forum
- implementing the DSSP
- developing the First Nations Disability Workforce.

The Forum should have the capacity to direct funding under the DSSP to:

- enable First Nations people with disability to provide advice and guidance from their lived experience to the Forum
- enable community-controlled organisations to develop their capacity to design and deliver disability-specific services and supports
- enable community-controlled organisations to work with other organisations to drive national leadership in disability policy and services reform
- enable community-controlled organisations to deliver on specific priority areas as identified in the DSSP

- enable the participation of community-controlled organisations not engaged in the Coalition of Aboriginal Peaks process
- support First Nations community-based organisations across the health, criminal justice and early childhood sectors to improve workforce disability competency to ensure First Nations people with disability receive appropriate disability support
- take into consideration the recommendations of the Royal Commission.

The Forum should develop and implement a strategy, supported by the First Nations disability investment fund, to build disability-specific expertise into First Nations Community Controlled Organisations.

Recommendation 9.11 Building on the Disability Sector Strengthening Plan

Parties to the National Agreement on Closing the Gap should commit to releasing a revised Disability Sector Strengthening Plan (DSSP) in partnership with the First Nations Disability Forum by the end September of 2024. The revised DSSP should have:

- agreed priority areas, determined through consultation with the community-controlled sector under the guidance of First People's Disability Network
- a commitment to future funding and longer timeframes
- agreed timeframes for delivering actions and achieving outcomes
- annual reporting requirements for government parties to the National Agreement on Closing the Gap.

Recommendation 9.12 Disability-inclusive cultural safety standards

The Australian Government in partnership with the First Nations Disability Forum should develop disability-inclusive cultural safety standards for the provision of services for First Nations people with disability.

Disability service providers that support and have a responsibility for First Nations people with disability, including in the health, criminal justice and early childhood sectors, should incorporate these disability-inclusive cultural safety standards in their practices and organisations.

Recommendation 9.13 Remote workforce development

The First Nations Disability Forum and parties to the Disability Sector Strengthening Plan (DSSP) should collaborate to develop a strategy to develop First Nations local workforces in remote communities. The strategy should consider:

- funding for community-level assessments to determine:
  - existing infrastructure and resources
  - the capacity and willingness of the First Nations community-controlled sector to support local workforce development
  - the level of demand within the community
- that allocation of funding for local workforce development should include funding to build the capacity of family members to provide care
- the strategy should be co-developed and co-implemented with First Nations Community Controlled Organisations, noting their capacity, expertise and willingness to be involved. The involvement of First Nations Community Controlled Organisations must be adequately supported and funded.

1. Introduction

> It is difficult to think of any more disadvantaged Australians than Aboriginal and Torres Strait Islander people with disability …[1]

The Royal Commission acknowledges and pays tribute to the many First Nations people with disability, families, carers and advocates who have fought for the rights of First Nations people with disability. We honour their commitment, strength and resilience.

We acknowledge the devastating and ongoing impacts of colonisation, dispossession and lack of recognition of First Nations people. We recognise the 'double disadvantage' of racism and ableism experienced by many First Nations people with disability.[2] We recognise the intersectional experiences that affect First Nations people with disability because of their gender, LGBTIQA+ identity, or as children and young people. It is with this understanding we have undertaken our work.

Our terms of reference directed us to examine the specific experiences of violence against, and abuse, neglect and exploitation of, First Nations people with disability, whatever the setting or context. We have spoken to hundreds of First Nations people with disability, their families, supporters and advocates, and peak bodies and service providers who want to see better outcomes for First Nations people with disability. It is a message echoed by many non-Indigenous people.

The oral and written evidence we have considered is in many ways a storyline 235 years in the making. A storyline is made up of voices that speak the stories of our past and its connection to the present. In this case, the voices tell of the violence, abuse, neglect and exploitation experienced by First Nations people with disability, what needs to change, and what works to provide culturally safe disability services to First Nations people. We witnessed these stories during the public hearings, private sessions and community engagements we have conducted, and the submissions we have received.

The past 30 years in particular have been both productive and challenging for First Nations people, including First Nations people with disability. First Nations people continue to call for self-determination. Intergenerational trauma continues to ripple through families and communities as the legacy of colonisation and dispossession. The issues of over-incarceration of First Nations people, Aboriginal deaths in custody, and child removal continue unresolved.

The campaign to Close the Gap arose following the *Social Justice Report 2005* from then Aboriginal and Torres Strait Islander Social Justice Commissioner, Professor Tom Calma AO. The report and subsequent campaign highlighted the combined national crises for First Nations people across life expectancy, health, education and employment. In 2020, the Coalition of

Aboriginal and Torres Strait Islander Peak Organisations and all Australian governments signed the National Agreement on Closing the Gap (National Agreement). However, there was little focus on disability because there was no broadbased network of grassroots organisations collectively highlighting the plight of Aboriginal and Torres Strait Islander people with disability.

In 2008, Australia ratified the *Convention on the Rights of Persons with Disabilities* (*CRPD*).[3] This landmark convention reaffirmed the human rights of people with disability. The following year, the Australian Government endorsed the United Nations *Declaration on the Rights of Indigenous Peoples* (*UNDRIP*).[4] While the *CRPD* and *UNDRIP* reflect significant progress in international human rights law, they fail to respond to the intersectional experiences of First Nations people with disability. In many ways, this reflects the different worlds First Nations people with disability walk in. Neither the *CRPD* nor the *UNDRIP* recognise First Nations people with disability contend with racism and ableism, as part of the 'double discrimination' that further disempowers them and entrenches structural disadvantage.[5]

In 2018, Dr Scott Avery's research report, *Culture is inclusion,* described the unique forms of 'intersectional discrimination' and social inequality experienced by First Nations people with disability.[6] It proposed a culture of inclusion as a positive force to create a pathway to social health and wellbeing.[7]

During our community engagements, we heard that some members of the First Nations community feel 'Royal Commission fatigue', doubting this inquiry could bring about real difference in the lives of 'our mob' with disabilities. We acknowledge and understand that fatigue. However, this Royal Commission has for the first time given the stories of Aboriginal and Torres Strait Islander people with disability national exposure.

As First Nations people with disability and their families add their stories to the record, they become the building blocks for change. We say to Australia, with the respect and honour due to our brothers and sisters with disability, these stories, experiences and solutions require our active attention. Now is the time for all of us to listen, to understand, and to act.

Our work is based on a foundation of Aboriginal and Torres Strait Islander self-determination. We see the National Agreement as a vehicle to drive further change. There are resilient, determined and innovative First Nations leaders, advocates and workers waiting for the opportunity to take this work forward.

This Royal Commission seeks to advance the story of Aboriginal and Torres Strait Islander rights in Australia by including First Nations people with disability. In providing this record, we hope First Nations people with disability experience equity and justice, taking their place in their communities as part of an inclusive Australian society.

1.1. Our approach to First Nations people with disability

The terms of reference directed us to have regard to the multilayered experiences of violence against, and abuse, neglect and exploitation of, people with disability, including the particular situation of Aboriginal and Torres Strait Islander people with disability.[8] We understood this as a direction to recognise the unique histories, cultures and associations with land, family, language and lore held by First Nations peoples. We also understood it to be a direction to consider the unique forms of disadvantage faced by First Nations people with disability.

This volume builds on the experiences of, and issues relevant to, First Nations people with disability interwoven throughout this *Final report*. It should be read in the context of the other volumes of the *Final report,* which also address First Nations issues and make relevant recommendations. This volume concentrates on elevating the voices of First Nations people with disability, their families and communities.

As Commissioner Mason, a Ngaanyatjarra and Pitjantjatjara woman, observed at the Royal Commission's first public hearing:

> First Nations people are already marginalised in the Australian community. Having a disability makes them part of a marginalised group, within a marginalised group. They experience racism and ethnocentrism, like other First Nations brothers and sisters experience. However, they see, hear and feel a greater level of discrimination above what I and other brothers and sisters experience because they have a disability.[9]

We recognise the First Nations disability community has many voices, as does the First Nations community. Consequently, we sought views from a wide range of independent organisations and community groups, and engaged with the people and organisations to give us a broad picture of the intersectional experiences of First Nations people with disability.

First Nations peoples are the experts in their own experiences. They have particular ways of working based on cultural protocols and governance systems. Our interactions with First Nations people with disability and their communities were guided by our *First Nations Engagement Principles*, summarised in Appendix A. Our approach placed First Nations people with disability at the centre of our work and was committed to ensuring cultural safety for everybody.

First Nations Peoples Strategic Advisory Group

The First Nations Peoples Strategic Advisory Group supported our work by providing leadership and guidance. This included advice on how the *CRPD* and *UNDRIP* should be implemented for the benefit of First Nations people with disability.

The group comprised seven community members who are First Nations people with specialist experience in the disability sector, three of whom have lived experience of disability. It was co-chaired by Commissioner Mason and Commissioner Galbally. In appointing external First Nations members, we honoured the disability sector's call of 'nothing about us without us' to enable the Royal Commission to connect with and directly listen to First Nations people with lived experience of disability.

Ms Joanna Agius OAM

Ms Joanna Agius is a Narungga woman from South Australia who is profoundly Deaf. She also has connections to the Kaurna, Ngarrindjeri and Wirangu nations in South Australia. She is a strong advocate for Deaf or hard of hearing Indigenous people. Ms Agius has taught Auslan since 2005 and is a lecturer at TAFE SA, delivering Auslan courses. She was awarded the Medal of the Order of Australia (OAM) in 2020 for service to people who are Deaf or hard of hearing, and to Indigenous communities.

Ms Jody Barney

Ms Jody Barney is a Deaf Birri Gubba / Urangan Aboriginal and South Sea Islander woman from Queensland who has lived for many years in regional Victoria. She is the founder of Deaf Indigenous Community Consultancy Pty Ltd and has worked in this field for more than 35 years. Ms Barney has worked as an expert communications consultant for Deaf Mob with Disabilities at the local, state and national levels, and can understand and communicate in over 20 First Nations sign languages. Ms Barney mentors, cultivates and supports a network of First Nations women with disability and their allies. She supports them to hone their skills and create belonging in their communities.

Ms Barney stepped down from the First Nations Peoples Strategic Advisory Group in early 2022. However, she continued to support the work of the Royal Commission, including as a witness at Public hearing 25, ‘The operation of the NDIS for First Nations people with disability in remote and very remote communities’ and Public hearing 27, ‘Conditions in detention in the criminal justice system’.

Mr Jake Briggs

Mr Jake Briggs is a Wonnarua / Kamilaroi man from New South Wales, who is a C5/C6 quadriplegic and a strong advocate for people with disability. Mr Briggs is managing director of Culture Connex, a National Disability Insurance Scheme (NDIS) service provider operating throughout Australia. Previously, he worked as a project and business development manager within the disability sector for the First Peoples Disability Network and has held various senior management roles. He currently holds advisory roles on disability topics for government and private sectors. Mr Briggs has produced a podcast, ‘Keep Rolling’, giving people a platform to tell their story.

Mr Damian Griffis

Mr Damian Griffis is a descendant of the Worimi people from New South Wales. He is a leading advocate for the human rights of Aboriginal and Torres Strait Islander people with disability. Mr Griffis is CEO of, and was a key figure in establishing, the First Peoples Disability Network Australia (FPDN), representing First Nations people with disability and their families at regional, national and international forums. He also helped to establish the Aboriginal Disability Network NSW. Mr Griffis won the Tony Fitzgerald (Community Individual) Memorial Award at the Australian Human Rights Awards in 2004. Mr Griffis was a witness at Public hearing 5, ‘Experiences of people with disability during the ongoing COVID-19 Pandemic’, Public hearing 18, ‘The human rights of people with disability and making the Convention on the Rights of Persons with Disabilities a reality in Australian law, policies and practices’ and Public hearing 25, ‘The operation of the NDIS for First Nations people with disability in remote and very remote communities’.

Dr Jackie Huggins AM FAHA

Dr Jackie Huggins is a Bidjara / Birri Guba Juru woman from Queensland. She is also an author and historian who has held many important positions including Co-Chair, Reconciliation Australia, Council for Aboriginal Reconciliation and Co-Chair of the National Congress of Australia’s First Peoples (where she represented First Nations people at the United Nations). She was Commissioner for Queensland of the National Inquiry into the Separation of Aboriginal and Torres Strait Islander Children from Their Families (The Stolen Generation). Dr Huggins is an Adjunct Professor at the Australian Centre for Indigenous History at the Australian National University in Canberra, and honorary Vice-Chancellor Fellow in Indigenous Leadership at Swinburne University. She serves as co-chair of the National Apology Foundation, the First Nations Advisory Committee Australian War Memorial, and the First Nations Messaging Project ‘Passing the Message Stick’ with Australian Progress.

Dr Huggins participated in the 2017 Uluṟu Statement from the Heart constitutional convention and was appointed Co-Chair of the Treaty Advancement Committee, which will lead Queenslanders on a Treaty process.

Dr Hannah McGlade

Dr Hannah McGlade is a Noongar woman from Western Australia. She is a lawyer, academic and human rights advocate. Her career has focused on justice issues for Aboriginal people, race discrimination law and practice, Aboriginal women and children, family violence and sexual assault. She has been a writer, researcher and conference speaker and has held a range of professional positions concerning issues affecting Aboriginal women and children. Dr McGlade is a member of the United Nations Permanent Forum for Indigenous Issues, the Western Australia Mental Health Tribunal and the Medical Board of Australia.

Aunty Louisa Uta

Aunty Louisa is an Elder in her Torres Strait Islander community in Queensland and has been a full-time carer for her mother, who uses a wheelchair, and her son, who lives with cerebral palsy. Aunty Louisa is a member of FPDN and Elders Living with Disability Australia, and a panel member of Every Australian Counts. She was a member of Carers Queensland’s Reconciliation Action Plan Steering Committee in 2015.

More information about the First Nations Peoples Strategic Advisory Group is included in Volume 2, *About the Royal Commission.*

Community engagement

We met First Nations people with disability, their families, carers and advocates across Australia. It was important to hear firsthand the stories of violence, abuse, neglect and exploitation. Visiting communities across the nation helped us understand their diverse experiences.

The expertise of our First Nations staff was key to this. The First Nations Engagement team had a gender balance, with members from different First Nations communities across Australia who had lived experience of disability and trauma. Members also represented the LGBTIQA+ community. Most importantly, the Engagement team had vital experience in, and established relationships with, First Nations communities. The role of our staff who could speak and understand local languages was also critical. This meant we had a diverse array of cultural knowledge to draw from in undertaking our work.

Commissioner Mason often joined the First Nations Engagement team as they undertook face-to-face engagements. The team visited urban, rural, remote and very remote locations in the Northern Territory, Victoria, South Australia, New South Wales, Western Australia, Tasmania and Queensland, including the Torres Strait and Northern Peninsula Area. The team usually spent two weeks in each region and was helped by local connectors to directly contact community members.

The First Nations Peoples Strategic Advisory Group identified geographical, thematic and stakeholder priority areas for First Nations community engagement. Through this process, the advisory group identified the difficulty of accessing the stories of First Nations people with disability who lived in closed settings. It looked at ways of reaching First Nations people with disability in places such as prisons, youth detention facilities, forensic mental health and forensic disability facilities. It also looked at how to reach First Nations children in out-of-home care.

All engagements were conducted in a way and in settings participants found comfortable and accessible. We held meetings in homes and community places, as well as on front lawns, under trees, in town camps, and on park benches. In the Torres Strait, we held some meetings while walking along the beach. Where possible, the team also made themselves available to the community after work hours and on weekends to provide as much flexibility and opportunity for people to share their stories and information.

The community engagement work played a critical role in identifying key issues that we could use to inform our public hearings, policy, and research and data analysis.

Image 9.1. A community passing the message stick to the Royal Commission, taken from 'Respectful Listening' by Wiradjuri artist and disability advocate Uncle Paul Constable Calcott

More information on our First Nations community engagements, including an overview of each engagement, is included in Volume 2, *About the Royal Commission.*

Public hearings

Public hearings are the means by which we obtained evidence under the *Royal Commissions Act 1902* (Cth). They provided an opportunity to hear from many people with disability who have experienced violence, abuse, neglect and exploitation.

The First Nations Peoples Strategic Advisory Group advised the Royal Commission on First Nations approaches to and priority areas for public hearings, including:

- Public hearing 8, 'The experiences of First Nations people with disability and their families in contact with child protection systems'
- Public hearing 11, 'The experiences of people with cognitive disability in the criminal justice system'
- Public hearing 16, 'First Nations children with disability in out-of-home care'
- Public hearing 25, 'The operation of the NDIS for First Nations people with disability in remote and very remote communities'
- Public Hearing 27, 'Conditions in detention in the criminal justice system'.

The Royal Commission included First Nations content and witnesses wherever it was possible in all public hearings, not just those focused on First Nations issues. We received evidence from 83 First Nations people, including 36 First Nations people with disability, across our public hearings. We draw on this evidence throughout this volume.

Image 9.2. First Nations people being heard at a public hearing, taken from 'Respectful Listening' by Wiradjuri artist and disability advocate Uncle Paul Constable Calcott

First Nations counsellors were available to provide appropriate cultural and emotional support to First Nations witnesses at our public hearings.

Private sessions

A private session is a confidential meeting between an individual and a Commissioner, held at the individual's request. Only persons who are authorised by the Commissioner holding the session may attend.[10]

Private sessions allowed people to meet individually with a Commissioner to share their story in a confidential environment. Just over 10 per cent of people who participated in a private session identified as First Nations.[11] More information about private sessions is included in Volume 2, *About the Royal Commission*.

Image 9.3. A First Nations person meeting with a Commissioner in a private session, taken from 'Respectful Listening' by Wiradjuri artist and disability advocate Uncle Paul Constable Calcott

First Nations-focused research

The Royal Commission recognised the importance of a comprehensive research agenda to inform our inquiry and to provide an evidence base to support our work and recommendations. Our research program was informed by what we learned in public hearings and private sessions, as well as from submissions and responses to issues papers, and in engagement meetings and our advisory groups. While all our research projects considered the experiences of First Nations people with disability, we commissioned a number of research projects focused particularly on issues relevant to First Nations people with disability.

Our research projects provide a legacy of disability research to address gaps in our understanding of the factors that contribute to the violence, abuse, neglect and exploitation that people with disability experience. These research projects are described below. More information on the Royal Commission's research agenda is included in Volume 2, *About the Royal Commission.*

Something stronger: Truth-telling on hurt and loss, strength and healing, from First Nations people with disability

Scott Avery

The purpose of this research report was to support engagement with the First Nations disability community that is considerate of their cultural values and beliefs on disability and inclusion, and acknowledges the unique traumas arising from their experiences of social isolation, inequality and discrimination. It builds upon a comprehensive program of research led from within the First Peoples Disability Network, a non-government community organisation established by and for Aboriginal and Torres Strait Islander people with disability. The research sourced the testimonies of 47 Aboriginal and Torres Strait Islander people with disability.

The research report focuses on testimonies that disclosed incidents of violence. It addresses two research questions. How do First Peoples with disability speak about their encounters of violence, abuse, neglect and exploitation? How do First Peoples with disability articulate their aspirations of empowerment, self-determination, inclusion and belonging, and how does this contrast with their description of their reality?

The First Nations Peoples Strategic Advisory Group recommended this research report be translated into First Nations languages to enable First Nations people with disability and their carers access to our work. It was translated into the following five First Nations languages:

- Djambarrpuynu Yolngu Matha
- Kimberley Kriol
- Pitjantjatjara
- Yumplatok
- Warlpiri.

Care criminalisation of children with disability in child protection systems

Susan Baidawi, Rubini Ball, Robyn Newitt, Lena Turnbull, Gayatri Kembhavi-Tam, Scott Avery and Rosemary Sheehan

The purpose of this research was to improve understanding of the pathways that lead children with disability from their contact with child protection system to entering the criminal justice system. The research also assessed the effectiveness of interventions aimed at preventing children with disability from taking these pathways. This is the largest Australian study so far to focus attention on children with overlapping experiences of child protection, disability and criminalisation. It also focused on the experiences of Aboriginal and Torres Strait Islander and culturally and linguistically diverse children who have these overlapping experiences.

Wangkiny Yirra 'Speaking up' Project: First Nations women and children with disability and their experiences of family and domestic violence

Jocelyn Jones, Lynn Roarty, John Gilroy, Juliet Brook, Mandy Wilson, Cathy Garlett, Hannah McGlade, Robyn Williams and Helen Leonard

First Nations women and children with disability are at greater risk of family and domestic violence and its consequences than their non-Indigenous peers. The purpose of this research was to engage with First Nations women and children and key stakeholders in Western

Australia to gain an understanding of their experiences of family and domestic violence. The research would identify factors that these women and children believe open them up to the risk of harm, and document their observations and experiences of barriers and enablers to seeking assistance and support. The research also sought to obtain their views on what works in currently available programs, and make recommendations for future culturally safe prevention and protection programs.

Options to improve service availability and accessibility for First Nations people with disability

Deloitte

The purpose of this research report was to provide a current and future forecast of service demand for disability services for First Nations people with disability. It considers the workforce skills and capabilities needed to support culturally appropriate services for them from a national and local perspective.

The research report found the First Nations disability service sector requires urgent reform to better provide for First Nations people with disability. This critical sector is unable to provide services backed by qualifications, quality and cultural safety standards in the numbers and locations required. The report proposed several recommendations to better realise service availability and accessibility.

Parents with disability and their experiences of child protection systems

Terri Libesman, Paul Gray, Eloise Chandler, Linda Briskman, Aminath Didi and Scott Avery

This research sought to improve understanding of the experiences of parents with disability of Australian child protection systems, paying particular attention to the experiences of First Nations and culturally and linguistically diverse parents with disability. It looked at the experiences of parents with disability across the spectrum of engagement with child protection systems, from initial reports of child protection concerns to out-of-home care, and restoration or permanent removal. It also addressed how child protection systems meet or breach the rights of parents with disability, and the reform necessary to reduce the risk of parents with disability and their families coming into contact with child projection systems. It also looked at examples of promising practice to improve outcomes for parents with disability and their families.

Submissions and issues papers responses

Submissions were one of the key ways individuals, groups and organisations shared experiences and insights with us. They often proposed recommendations for our consideration. In addition to submissions from individuals, we received them from research organisations, disability advocacy organisations, peak bodies, government departments and agencies, and professional organisations.

The submissions process was flexible. People could make submissions by email, post or telephone and in any language, including Auslan and Australian Indigenous languages. They could be made in any format the person felt comfortable with, including video and audio.

We collated and analysed the experiences and views of individuals and organisations detailed in the 7,944 submissions that we received. Around 8 per cent of submissions were from First Nations people. More information about the submissions we received can be found in Volume 2, *About the Royal Commission.*

The issues paper on the *Experiences of First Nations people with disability in Australia* was published on 9 June 2020. We received 23 responses. The First Nations Peoples Strategic Advisory Group provided advice about the *Overview of responses to the experiences of First Nations people with disability issues paper*.[12] It recommended translating selected First Nations research material into First Nations languages.

Responses to other issues papers also addressed issues relevant to First Nations people with disability. Many of them told us about their experiences of racism, discrimination and lack of support within education, justice – including interactions with police, forensic facilities and legal settings – and closed institutional settings.

Voices of First Nations people

We learned from the generous contributions of First Nations people with disability in the various forums they chose to engage with us. The people who shared their experiences with us in private sessions, submissions, community engagements and workshops were not witnesses, in that they did not take an oath or give an affirmation to contribute formal evidence to this inquiry. The *Royal Commission Act 1902* (Cth) expressly provides that a person who appears at a private session is not a witness and does not give evidence. Accordingly, the first-hand accounts included in this volume do not represent findings of the Royal Commission. Rather, we acknowledge these as personal experiences and the importance of the voices of First Nations people with disability finally being heard.

1.2. Understanding rights within a First Nations framework

Our work was informed by human rights relevant to First Nations peoples as a distinct cultural group, as well as their rights as individuals with disability. We were guided by the *CRPD* and *UNDRIP.*

The *CRPD* and First Nations people with disability

Although the creation of the *CRPD* was a significant development for people with disability, it does not specifically address the rights of Indigenous people with disability. This has been identified as a shortcoming of the treaty.[13] The only reference to indigenous people is in the preamble, which notes 'concern' about the 'difficult conditions' faced by people with disability on the basis of 'indigenous status'.[14]

Dr Scott Avery identifies how:

> [t]he absence of a direct reference to Indigenous disability rights within the body of the *CRPD* dilutes the legal obligation upon signatory nations to implement mechanisms that advance the rights of Indigenous people with disability.[15]

In Public hearing 18, 'The human rights of people with disability and making the Convention on the Rights of Persons with Disabilities a reality in Australian law, policies and practices', Mr Damian Griffis, CEO of FPDN, gave evidence about the ability of the *CRPD* to protect the rights of First Nations people.[16] Mr Griffis said:

> when the [*CRPD*] was written up, there were no Indigenous voices there during the process of actual writing up of the Convention. So we worry that that is still a shortcoming of the Convention.[17]

However, Mr Griffis also acknowledged the rights of First Nations people with disability are being 'increasingly recognised' by the CRPD Committee.[18] For example, issues relevant to First Nations people with disability in Australia were included in the CRPD Committee's Concluding Observations on the combined second and third periodic reports on Australia.[19] Of particular note, the CRPD Committee acknowledged:

- the difficulties faced by First Nations people with disability in accessing services through the NDIS[20]
- the need to involve First Nations people with disability and their representative organisations in all aspects of the design, implementation and monitoring of the Australian Government Plan to Improve Outcomes for First Nations People with Disability.[21]

The *UNDRIP* and First Nations people with disability

Across our work, we have also considered other international human rights treaties, instruments and materials relevant to First Nations people with disability. The *UNDRIP* is a particularly important instrument recognising the rights of Indigenous peoples around the world.[22]

The *UNDRIP* does not create new rights for First Nations people with disability. Rather, it provides a 'contextualised elaboration' of how general, existing human rights principles relate to the 'specific historical, cultural and social circumstances of Indigenous peoples', as described by the Special Rapporteur on the Situation of Human Rights and Fundamental Freedoms of Indigenous People.[23]

While not legally binding as international law, the Australian Government has recognised the *UNDRIP* 'sets important international principles for nations to aspire to'.[24] The Australian Government has also affirmed that consideration of the human rights of First Nations people and people with disability (including rights expressed in the *CRPD* and *UNDRIP*) are central to its 'Plan to Improve Outcomes for Aboriginal and Torres Strait Islander People with Disability', 2017.[25] In Public hearing 25, ‘The operation of the NDIS for First Nations people with disability in remote and very remote communities’, Ms Patricia Turner AM, CEO of the National Aboriginal Community Controlled Health Organisation (NACCHO), described the *UNDRIP* as representing ‘one of the most significant developments in advocacy for indigenous people’s rights globally’.[26]

Key rights recognised in the *UNDRIP* particularly relevant to First Nations people with disability include the rights to safety and dignity, self-determination, health, respect for and protection of culture, equality, and non-discrimination.[27]

The *UNDRIP* asserts First Nations peoples’ rights to language, and culture and spiritual identity.[28] This includes the right to revitalise, use and pass on histories, traditions, languages and ways of understanding the world. As former Aboriginal and Torres Strait Islander Social Justice Commissioner, Mr Mick Gooda, has commented, the *UNDRIP* and its emphasis on the right to culture ‘means we have a right to practice our culture and make sure our culture survives and grows’.[29]

The rights of First Nations people with disability are tied to their holistic physical, cultural and spiritual health and wellbeing.[30] The Victorian Aboriginal Community Controlled Health Organisation emphasised that the right to culture and community should not be separated from their disability needs.[31]

Articles 21 and 22 of the *UNDRIP* make specific reference to indigenous people with disability. Article 21 states that ‘indigenous peoples have the right, without discrimination, to the improvement of their economic and social conditions’,[32] and requires States to pay ‘particular attention’ to the needs of indigenous people with disability.[33] Article 22 reinforces this by providing that States, when implementing the *UNDRIP*, should pay ‘particular attention’ to the ‘rights and special needs’ of indigenous people with disability.[34]

According to a study by the UN Permanent Forum on Indigenous Issues:

> implementing the [*CRPD*] in a way that also respects the Declaration means that, whenever relevant, the measures foreseen in the [*CRPD*] will need to be applied in a way that is sensitive to the culture and world vision of indigenous peoples in order to best protect the rights of indigenous persons with disabilities.[35]

We have sought to adopt this approach across our work.

Uluṟu Statement from the Heart

More recently, the Uluṟu Statement from the Heart developed a position on Indigenous constitutional recognition based on self-determination and the centrality of culture to enable First Nations children to thrive:

> We seek constitutional reforms to empower our people and take a rightful place in our own country. When we have power over our destiny our children will flourish. They will walk in two worlds and their culture will be a gift to their country.[36]

Evidence provided to the Royal Commission noted the importance of the Uluṟu Statement from the Heart and its promise for legislation to enable First Nations people to advise on legislation that affects them.[37] In Public hearing 25, Mr Griffis said he hoped a Voice to Parliament would include a standing committee on disability.[38]

We were told constitutional recognition of First Nations peoples is critical for the NDIS and health systems to work better for people with cognitive disability.[39] We heard a commitment to such reform is an essential precondition for the safety and wellbeing of First Nations people with disability and for achieving justice and equity in health and legal systems.[40]

1.3. The impact of colonisation on First Nations people with disability

> … the ‘trauma story’ of Aboriginal and Torres Strait Islander people with disability is an impairment uniquely experienced by Aboriginal and Torres Strait Islander people who have been dispossessed from both Country and body.[41]

Through the lasting footprints of the ‘Mungo Man’ and other historical evidence, we know First Nations people with disability played active roles in early society.[42] Prior to colonisation, they were included in social and cultural life and had responsibilities as part of First Nations communities. We heard that disability was just ‘part of the human experience’.[43]

The cataclysmic impact of European colonisation on First Nations people is well known. The experiences of First Nations people with disability cannot be separated from the ongoing impacts of colonisation, intergenerational trauma and institutional racism experienced by First Nations people more generally.

Colonisation had a unique impact on Aboriginal and Torres Strait Islander people with disability. Dr Avery describes its particular consequences in *Culture is inclusion*, writing that while subject to the same dispossession as the broader Aboriginal population, they were also dehumanised as they ‘acquired a new label of “disability”’.[44] Dr Avery argues this ‘social “othering”’ increased the marginalisation of First Nations people with disability, even within their own communities.[45]

The enduring legacy of colonisation and intergenerational trauma is reflected in the story of Ms Marmingee Hand, a Walmajarri woman from Fitzroy Crossing.[46] She told us about her family’s ‘painful’ experience with how disability has previously been ‘managed’ in Australia.[47] Of her two sisters, one was mis-diagnosed with leprosy and forcibly removed to a leprosarium.[48] The other was diagnosed with a mild intellectual disability, and forcibly removed to Perth, more than 2,300 kilometres away from her Country and family.[49] Ms Hand described how these events have influenced the experiences of the present generation. She told us about the impact on her sister's children, in particular her son Tristan, who has been diagnosed with fetal alcohol spectrum disorder. Ms Hand told us:

> The trauma of both of these experiences had a profound impact on my whole family, and especially my mother. As the eldest sibling I felt a lot of responsibility and it affected me deeply. In part as a result of this trauma, Tristan and his older sister were on a path of removal when we took them in. My sister was not able to look after Tristan with all his medical needs. He was in danger of becoming a ward of the state but Geoff and I were able to take him in and raise him as our own son.
>
> For Geoff and I, it was really important that we break that cycle. We didn't want Tristan and his sister be removed from their family as well because of their disability.[50]

Ms Hand felt her personal experience was reflected more broadly in the community at Fitzroy Crossing.

> The intergenerational trauma that Aboriginal people faced throughout their lives … is really the cause of all the stuff that is happening now.[51]

Chapter 2 discusses the legacy of colonisation for First Nations people with disability through intergenerational trauma and beyond.

1.4. First Nations disability policy

First Nations people with disability are uniquely marginalised in Australia. The prevalence of disability is much higher in First Nations populations than in the general population. First Nations people with disability also experience high rates of violence and abuse, particularly First Nations women with disability, as discussed in Chapter 4.

First Nations people with disability sit at the intersection of multiple strategies and frameworks. This volume looks at gaps and omissions in the National Agreement, Australia's Disability Strategy 2021–2031 (ADS) and NDIS strategies and plans for implementation. First Nations disability policy is also inadequately covered in the National Framework for Protecting Australia's Children 2021–2031 and the National Plan to End Violence against Women and Children 2022–2032.[52]

Despite the high prevalence of disability among First Nations communities and high rates of violence and abuse, the needs of First Nations people with disability are largely overlooked by national policy frameworks. This was a common thread through several of our public hearings.[53] At Public hearing 4, 'Health care and services for people with cognitive disability', Dr Avery spoke of the 'game of tennis' that bounces responsibility for Aboriginal people with disability between different plans and strategies.[54] At Public hearing 17, 'The experience of women and girls with disability with a particular focus on family, domestic and sexual violence', Ms Thelma Schwartz, Principal Legal Officer at the Queensland Indigenous Family Violence Legal

Service, described the ‘invisibility’ of First Nations women and girls with disability in public policy generally. She agreed that while the National Agreement is a vehicle to drive change, significant further work is needed.[55]

Chapter 8, ‘The case for structural reform’, examines these issues in more detail and makes recommendations to strengthen the voices of First Nations people with disability.

Endnotes

1 Exhibit 5-34, ‘Statement of Damian Griffis’, 11 August 2020, at [9].

2 Lester Bostock, ‘Access and equity for people with a double disadvantage’, (1991), vol 2, Australian Disability Review, pp 3–8.

3 *Convention on the Rights of Persons with Disabilities*, opened for signature 30 March 2007, 2515 UNTS 3 (entered into force 3 May 2008).

4 Jenny Macklin, Minister for Families, Housing, Community Services and Indigenous Affairs, *Statement on the United Nations Declaration on the Rights of Indigenous Peoples*, statement, Canberra, 3 April 2009; United Nations General Assembly, United Nations Declaration on the Rights of Indigenous Persons, GA Res 61/295, UN Doc A/RES/61/295 (2 October 2007, adopted 13 September 2007).

5 Exhibit 4-18, ‘Statement of Dr Scott Avery’, 24 February 2020, at [36].

6 Scott Avery, *Culture is inclusion: A narrative of Aboriginal and Torres Strait Islander people with disability*, First Peoples Disability Network Australia, 2018, p v.

7 Scott Avery, *Culture is inclusion: A narrative of Aboriginal and Torres Strait Islander people with disability*, First Peoples Disability Network Australia, 2018, p v.

8 *Letters Patent* (Cth), 4 April 2019 (as amended) [g].

9 Transcript, Andrea Mason (Commissioner), Public hearing 1, 16 September 2019, P-5 [35–39].

10 *Royal Commissions Act 1902* (Cth) s 6OG.

11 More information about private sessions is available in Volume 2, *About the Royal Commission.*

12 Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, *The experience of First Nations people with disability in Australia issues paper*, June 2020.

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18 Transcript, Damian Griffis, Public hearing 18, 8 November 2021, P-58 [19–21].

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20 Committee on the Rights of Persons with Disabilities, *Combined second and third periodic reports submitted by Australia under article 35 of the Convention, due in 2018: Convention on the Rights of Persons with Disabilities,* 22nd session, UN CRPD/C/AUS/2-3, (23 September 2019).

21 Committee on the Rights of Persons with Disabilities, *Combined second and third periodic reports submitted by Australia under article 35 of the Convention, due in 2018: Convention on the Rights of Persons with Disabilities,* 22nd session, UN CRPD/C/AUS/2-3, (23 September 2019).

22 United Nations, *United Nations Declaration on the Rights of Indigenous Peoples*, UN Doc A/RES/61/295 (13 September 2008); Australian Human Rights Commission, ‘UN Declaration on the Rights of Indigenous Peoples’, web page. <www.humanrights.gov.au/our-work/un-declaration-rights-indigenous-peoples-1>.

23 S James Anaya, *Report of the Special Rapporteur on the Situation of Human Rights and Fundamental Freedoms of Indigenous People*, UN Doc A/HRC/9/9, (11 August 2008), p 24 [86].

24 Jenny Macklin, Minister for Families, Housing, Community Services and Indigenous Affairs, *Statement on the United Nations Declaration on the Rights of Indigenous Peoples,* statement, Canberra, 3 April 2009, p 2.

25 Department of Social Services, *Australian Government Plan to Improve Outcomes for Aboriginal and Torres Strait Islander people with Disability,* 2017, p 11.

26 Exhibit 25-84, ‘Statement of Patricia Turner’, 27 June 2022, at [135].

27 United Nations, *United Nations Declaration on the Rights of Indigenous Peoples,* UN Doc A/RES/61/295, arts 4, 24, 11, 3.

28 United Nations, *United Nations Declaration on the Rights of Indigenous Peoples*, UN Doc A/RES/61/295, arts 11, 13, 14, 16, 25, 31, 34.

29 'The United Nations Declaration on the Rights of Indigenous Peoples' *Australian Human Rights Commission,* web page. <https://declaration.humanrights.gov.au/know-it/respect-and-protection-culture>

30 National Aboriginal Community Controlled Health Organisation, Submission in response to *Rights and attitudes issues paper*, 11 September 2020, ISS.001.00443, p 5.

31 Victorian Aboriginal Community Controlled Health Organisation, Submission in response to *The experience of First Nations people with disability in Australia issues paper*, 16 October 2020, ISS.001.00493, p 10.

32 United Nations, *United Nations Declaration on the Rights of Indigenous Peoples*, UN Doc A/RES/61/295, art 21(1).

33 United Nations, *United Nations Declaration on the Rights of Indigenous Peoples*, UN Doc A/RES/61/295, art 21(1).

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36 National Constitutional Convention, 'Uluṟu Statement from the Heart', 26 May 2017.

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41 Scott Avery, *Culture is inclusion: A narrative of Aboriginal and Torres Strait Islander people with disability*, First Peoples Disability Network Australia, 2018, p 9.

42 Scott Avery, *Culture is inclusion: A narrative of Aboriginal and Torres Strait Islander people with disability*, First Peoples Disability Network Australia, 2018, p 2; Steve Webb, 'Further research of the Willandra Lake fossil footprint site, southeastern Australia', (2007), vol 52 (6), *Journal of Human Evolution*, pp 711–15.

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44 Scott Avery, *Culture is inclusion: A narrative of Aboriginal and Torres Strait Islander people with disability*, First Peoples Disability Network Australia, 2018, p 9.

45 Scott Avery, *Culture is inclusion: A narrative of Aboriginal and Torres Strait Islander people with disability*, First Peoples Disability Network Australia, 2018, p 9.

46 Exhibit 25-40, 'Statement of Marmingee Hand', 4 July 2022, at [10–11].

47 Exhibit 25-40, 'Statement of Marmingee Hand', 4 July 2022, at [10–11].

48 Exhibit 25-40, 'Statement of Marmingee Hand', 4 July 2022, at [11].

49 Exhibit 25-40, 'Statement of Marmingee Hand', 4 July 2022, at [11].

50 Exhibit 25-40, 'Statement of Marmingee Hand', 4 July 2022, at [11–12].

51 Transcript, Marmingee Hand, Public hearing 25, 13 July 2022, P-190 [46–47], P-191 [1].

52 Transcript, Damian Griffis, Public hearing 25, 14 July 2022, P-269 [7–11], [35–45].

53 Exhibit 4-18, 'Statement of Dr Scott Avery', 24 February 2020, at [62], [63]; Transcript, Cheryl Axleby, Public hearing 11, 23 February 2021, P-466, [17–21]; Transcript, Thelma Schwartz, Public hearing 17, 13 October 2021, P-39, [1–15]; Transcript, Damian Griffis, Public hearing 25, 14 July 2022, P-269 [7–11], [35–45].

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2. Disability: ‘Not a word we use’

Key points

- First Nations cultural understandings of inclusion do not align with Western concepts of disability, particularly the Western tendency to focus on individual impairment over collective wellbeing.
- The medical model, with its focus on diagnosis and deficit, and the social model of disability, with its emphasis on social barriers, diverge from First Nations cultural practices.
- Many First Nations people with disability prefer a cultural model centred on inclusion. This approach recognises that inclusive participation in culture and community has a positive impact on social health and wellbeing, and moderates the harm of inequalities experienced in daily life.
- Colonisation, including historical policies, laws and practices, has affected the way disability is understood and experienced by First Nations people.
- The legacy of the Stolen Generations includes the devastating rupture of connection with family, culture and Country. It has also contributed to complex feelings of shame and guilt around disability.
- Some First Nations people with disability are reluctant to obtain a formal assessment or diagnosis, or engage with services, particularly government services.
- The reluctance to seek diagnosis, combined with shame, stigma and mistrust of government services, creates formidable barriers to accessing disability supports and services.
- First Nations people have expressed a strong desire for better access to appropriate, culturally safe disability supports and services.
- For services and supports to meet the needs of First Nations people with disability, they need to be informed by First Nations cultural values and practices. An emphasis on cultural safety, and social and emotional wellbeing aligns with the First Nations concept of a cultural model of disability inclusion.

2.1. A culture of inclusion

> … the vast majority of Aboriginal and Torres Strait Islander people with disabilities do not identify as a person with disability. This is because in traditional language there was no comparable word for 'disability'. Also the vast majority of Aboriginal and Torres Strait Islanders with disabilities are reluctant to take on a further negative label – particularly if they already experience discrimination based on their Aboriginality.[1]

First Nations peoples' understanding of disability does not easily align with Western concepts of disability, particularly the tendency to focus on individual impairment over collective wellbeing. Aboriginal and Torres Strait Islander Social Justice Commissioner June Oscar AO stated, 'there is a stark difference in how our people view what is now commonly referred to as disability'.[2] First Nations peoples have different values, beliefs and social practices about health, wellbeing and how the body functions.[3]

First Nations people with disability are critical of the medical model of disability, which identifies disability as a problem to be fixed and leads to the exclusion of people with disability from the broader community.[4] Some First Nations people with disability are also critical of the social model of disability, with its emphasis on social deficits, preferring instead to emphasise cultures of inclusion.[5]

First Nations people described how people with disability are included within community life. Underpinning this is an understanding of differences between people as central to the flourishing of the community.[6] Commissioner Oscar AO said:

> [we] see their strengths and not their limitations. We see those people as having special gifts. They have a unique role in the cultural life of their communities, and they have a sense of belonging. People with disability have an extra special role because of their uniqueness.[7]

Ms Emily Carter and Dr Lauren Rice from Marninwarntikura Women's Resource Centre said, 'the language of disability is a western construct and is how the western world identifies people in need of supports, which is built into the NDIS system'.[8] They said many First Nations cultures instead 'perceive disability through a strengths-based approach, focusing on how people with disability can contribute to their community, rather than what they cannot do and their functional impairment'.[9]

We commissioned the Wangkiny Yirra ‘Speaking up’ research project to investigate First Nations women and children with disability’s experiences of family and domestic violence in Western Australia.[10] One participant in this research said:

> It’s not different being disability [sic], it’s just understanding there’s people that need something more than what they really need and that is spiritual by listening, feeling, and also being accepted.[11]

Mr Richard Weston, CEO of the Secretariat of National Aboriginal and Islander Child Care, told us First Nations communities do not see disability as a problem to be fixed, but as something to be incorporated and accommodated:

> We see it as this is part of who a person is, and it’s an issue that needs to be supported. And Aboriginal and Torres Strait Islander people that live with a disability are just as keen on their cultural connections and the valuing of their identity. When we look at a tree, if we look at a tree and it has got broken branches or we look at a tree that has been scorched by a bushfire, it’s still a tree. And, you know, children and families that live with a disability are still very much parts of our community.[12]

Yuin man and academic Professor John Gilroy and colleagues note First Nations communities do not have a word for ‘disability’, but rather a diverse range of approaches ‘as diverse as the cultures within the Indigenous population’.[13] In the Wangkiny Yirra ‘Speaking up’ research project, a Yawuru Elder said:

> We never use the word – we never understand the word of – the meaning of disability because we know that our children have different abilities to succeed. We nurture that ability so we just say ‘This one here we need to look after him. We need to help him a little bit more than the others’. So this is why we need to understand the interpretation of how we identify our young people or people with the needs to help them succeed.[14]

Dr Avery outlined how First Nations people tend to use words that describe different types of conditions, such as blindness, deafness, mental health, mobility difficulties and back pain, but not a generic catchall for disability. According to Dr Avery, these terms are used positively rather than negatively.[15]

During a community engagement in the Northern Territory, a physiotherapist working with clients with disability told us about a conversation with a First Nations man who had mobility issues. His client did not identify as having a disability, but said he had a ‘sleepy foot’ that needed to be woken up to help him walk better.[16]

A worker from a First Nations community organisation in Tasmania told us several of her clients did not identify as having a disability, possibly because of the associated stigma. She described one exchange with a client who said, ‘I don’t have a disability, I just have trouble learning stuff’.[17]

A workshop participant said:

> we're increasingly moving more and more into a warehousing, othering world, which is in complete conflict with our worldview of disability. This is part of the fundamental problems that we face. So there is no more heavily label-laden area than disability. Acquired brain injury, autism, intellectual impairment, physical disability: it's a long, long laundry list of impairments, and it's not the way we talk about disability. So brother there's a bit slower than everyone else. Uncle doesn't hear too well. Cousin doesn't move around too well. Not said in a negative way.[18]

During Public hearing 25, 'The operation of the NDIS for First Nations people with disability in remote and very remote communities', Ms June Riemer, Deputy CEO of FPDN, summarised the category of disability as a colonial concept, 'but for First Nations people, we are not about labelling'.[19] At Public hearing 25, Mr Griffis, CEO of FPDN, gave evidence about different understandings of disability. He said because First Nations people think differently about disability:

> it's come as you are, and we will do what we can to provide the supports so you can participate in community life. So, we want to change the conversation from medical model of disability to social model of disability to a culture of inclusion.[20]

In *Culture is inclusion,* Dr Avery describes a 'First Peoples cultural model of disability and inclusion', which recognises that inclusive participation in cultural and community events has a positive impact on social health and wellbeing, and moderates the harm of inequalities experienced in daily life.[21] His research found First Nations people with disability participate in social activities and events within their community at the same rate as First Nations people without disability, and are accepted and included along with everyone else.[22]

Dr Avery notes the First Nations culture of inclusion has survived despite other disruptive influences upon community functioning, such as colonisation.[23] He also observes how First Nations people with disability are required to walk in more than one world: within the world of their community, cultural identity and inclusion are emphasised, but 'to access the services they need in a non-cultural model, they effectively have to disable themselves, a concept that is antithetical to their core cultural beliefs'.[24]

2.2. Intergenerational trauma: the legacy of colonisation and the Stolen Generations

The reluctance of First Nations people with disability to identify with disability has a complex history. It is about more than cultural differences between First Nations and non-Indigenous people. It is also a product of stigma and shame about disability that results from colonisation, trauma and discriminatory treatment.[25]

Witnesses at Public hearing 8, 'The experiences of First Nations people with disability and their families in contact with child protection systems' and Public hearing 16, 'First Nations children with disability in out-of-home care' spoke about the ongoing impact of colonisation, dispossession and the Stolen Generations on First Nations families and communities. They shared the cycle of intergenerational trauma and the devastating effects on connections with family, culture and Country.[26] First Nations people with disability drew links between child removal and later contact with the criminal justice system, experiences of family and domestic violence, and poor education and health outcomes.[27] The evidence in these hearings described daily experiences of disadvantage and marginalisation for many First Nations parents and children with disability, against a backdrop of poverty, unemployment, and inadequate and unstable housing.

Mr Weston described the nature and effect of intergenerational trauma:

> Trauma is a person's response to a major catastrophic event that's so overwhelming it leaves that person unable to come to terms with it. In some cases, trauma is passed down from the first generation of survivors, who directly experienced or witnessed the traumatic event, to future generations. This is referred to as intergenerational trauma, and can be passed on through parenting practices, behavioural problems, violence, harmful substance abuse and mental health issues.
>
> It is generally understood that there are impacts of this trauma for Aboriginal and Torres Strait Islander families and communities, particularly if people have not had an opportunity to heal from it. They may unknowingly pass it on to others through their behaviour. For example, for parents, their children may experience difficulties with attachment, disconnection from their extended families and culture and high levels of stress from family and community members who are dealing with the impact of trauma. This creates a cycle of trauma, where the impact is passed from one generation to the next.[28]

Members of the Stolen Generations told us how they were cut off from their family and culture after being removed from their parents for having a disability. At a workshop, a Latje Latje man said he cycled through foster homes in Melbourne, far from the life he 'should have been living', with experiences of violence and abuse that had 'lifelong ramifications'.[29]

Parents with disability are at greater risk of having their children removed, and children with disability are more likely to be removed.[30] Several witnesses expressed the view that First Nations children's involvement in the child protection system cannot be separated from the experiences of poverty, inequality, trauma and adverse childhood experiences that often coincide with disability.[31] They said child protection authorities are more likely to pay attention to the parenting practices of the poor and disadvantaged.[32] This perspective is substantiated by research commissioned by the Royal Commission.[33]

We heard that a family history of removal creates a risk factor for children being removed from their families. The legacy of the Stolen Generations is that many families have a heightened risk of engagement with child protection systems:

> One of the issues that drives, creates a risk for Aboriginal and Torres Strait Islander children is that there is a previous history in the family of removal. Now, in Aboriginal and Torres Strait Islander communities, that risk is always there because of the Stolen Generations. You know, 100 years of taking children from families and culture just because they were Aboriginal based on a misguided notion around assimilation, that has created a history in our families of removal.[34]

The ongoing removal of First Nations children by child protection authorities in Australia perpetuates cycles of trauma. As Richard Weston said to us:

> Unfortunately, continued removal of Aboriginal and Torres Strait Islander children from their families and communities continues to weaken the essential relationships and the very nature of kinship systems that are the cornerstone of Aboriginal and Torres Strait Islander society and to their healing.[35]

For many First Nations families, fear of child protection systems and other government agencies is the legacy of the Stolen Generations.[36] Research we commissioned into the experiences of parents with disability with child protection systems identified how many First Nations parents with disability 'whose lived experiences, including the intergenerational trauma of the Stolen Generations' makes them 'highly attuned to the associated risks of increased surveillance of parents and families, and exposure to child protective services'.[37] Consequently, they may avoid identifying disability or access support, given the potential risks.[38]

Several witnesses said they felt the current high rates of child removal were creating another 'Stolen Generation'. Aunty Jenny Swan from Grandmas Against Removals said:

> You know, we've got higher rates than in the Stolen Generation now, I think it's 11 times higher than the Stolen Generation, that's never stopped. Names have changed, policies have changed, but that's never stopped.[39]

The evidence before the Royal Commission demonstrates First Nations children are over-represented in the child protection system. National data indicates that First Nations children account for 41 per cent of the children in out-of-home care.[40] National data also indicates that the number of First Nations children receiving child protection services is increasing.[41]

Describing the impact of the removal of children, Commissioner Oscar AO said:

> What we have is a system that removes children for 'neglect' when the environment causing that neglect is a product of the system itself.
>
> It is extraordinary that in this day and age we do not have a system that supports people adequately, but rather a system that perpetuates poverty and trauma.[42]

Commissioner Oscar AO said trauma 'dominates' the lives of First Nations people and communities today, and this trauma co-occurs with disabilities.[43]

We recognise unaddressed and intergenerational trauma can affect childhood development and be associated with developmental delay. We also understand such trauma can be associated with mental health conditions, including psychosocial disabilities, such as depression and anxiety.[44] We accept trauma is also associated with behaviours such as substance misuse, self-directed violence, violence against others and risk-taking that can result in acquired disability or disability of children (for example, fetal alcohol spectrum disorder (FASD) as a result of prenatal alcohol abuse).[45]

We agree with Commissioner Oscar AO, ‘we cannot address high rates of disability across our entire population … without understanding and addressing intergenerational trauma’.[46] We received evidence that intergenerational trauma of First Nations people can be misdiagnosed by practitioners as disability and that trauma might mask underlying disability among First Nations people.[47] Mr Weston stated distress on the part of a First Nations person is often assessed as the presentation of a mental health disorder rather than being viewed through the lens of a cultural trauma response framework.[48] Mr Weston and Commissioner Oscar AO explained the intergenerational trauma of First Nations people has not been sufficiently addressed by mental health service practitioners or in policy responses or services systems.[49]

In Public hearing 8, Ms Thelma Schwartz, Principal Legal Officer at the Queensland Indigenous Family Violence Legal Service, described working as a criminal defence solicitor representing people with diagnosed and undiagnosed disability:

> It’s been my experience that a high proportion of our clients will present to us with the sequelae of trauma. Trauma being either physical trauma from fleeing a physically violent relationship, or the trauma that’s associated, that would probably be called posttraumatic stress disorder which is undiagnosed. So these are the types of clients that we deal with on a day-to-day basis in my practice.[50]

2.3. The double disadvantage of racism and ableism

> I have often felt that I represent the three demographic groups in Australian society that are treated worst. I am First Nations, I am a woman and I have a disability. I have felt the impact and burden of all three of these things that are part of who I am.[51]

Colonisation and the Stolen Generations are not merely parts of history. They carry forward to the present day, not only through the trauma passed from one generation to the next, but also through the ongoing structural violence experienced by First Nations people.

Multiple past inquiries, including royal commissions, have examined the impact of the entrenched racism in Australia, its persistence within institutions and systems, and the enduring attitudes of non-Indigenous people toward First Nations people.[52] In its landmark 1991 report, the Royal Commission into Aboriginal Deaths in Custody identified racism as a central experience for Aboriginal people and fundamental to the concerns of that royal commission.[53] Based on the evidence and information presented to our Royal Commission, we do not believe this experience has significantly changed.

Witnesses at Public hearing 16 and Public hearing 17, ‘The experience of women and girls with disability with a particular focus on family, domestic and sexual violence’, described racism as an inherent part of systems in Australia, disproportionately affecting First Nations people with disability.[54] This structural and institutional racism ranges from the explicit to something, 'that you don't see, the things that you can't see, the things you can't put your finger on'.[55] Racism continues to collectively 'disable' First Nations people.[56]

Noting First Nations people with disability experience a double disadvantage at the intersection of racism and disability discrimination,[57] at Public hearing 4, 'Health care and services for people with cognitive disability', Dr Avery described how this generates social hierarchies that disempower First Nations people with disability:

> The cumulative effects of racism are such that Aboriginal and Torres Strait Islander [sic] are structurally disempowered compared to people who are not Indigenous. The cumulative effects of ableism are such that people with disability are structurally disempowered compared to people who do not have disability. Aboriginal and Torres Strait Islander people with disability must contend with racism, ableism, and an intersectional interaction of these forms of discrimination, structurally disempowering them further again.[58]

Dr Avery gave a contemporary example of how racism and ableism combine in the lives of First Nations people with disability. He described the testimony of an Aboriginal man in Western Sydney who has an intellectual disability. Because of stereotypes about First Nations people and alcohol, when he is out in public people misread the presentation of his cognitive impairment and assume he is drunk.[59]

We heard evidence that discrimination is further heightened for First Nations women with disability.[60] Ms Narelle Reynolds is a Wiradjuri woman, who has two sons and other family members diagnosed with Fragile X. At Public hearing 4, she described the discrimination she and her sons experience when trying to access services:

> Being Aboriginal on top of being a mother of children with intellectual disability is a double whammy. Being black and fighting through the health system is one thing, but fighting for sons with intellectual disability is another. I don't know if anyone can understand that. The majority of First Nations people are oppressed. Black fellas always have to comply with white rules. We have to ensure that our place in the world, that is rightfully ours, is safe. We have to show white people our own value. That's just the way it is.[61]

These intersectional experiences of discrimination are present in the child protection system. We have been told that racist and biased views held by child protection workers may be compounded further if parents are identified as having disability.[62] South Australian Commissioner for Aboriginal Children and Young People April Lawrie, a Mirning and Kokatha woman, described hearing from First Nations families that child protection staff are:

> wholly judgmental in terms of Aboriginality and their own discriminatory attitudes and beliefs and also overly judgmental about anyone that might be presenting with disabilities.[63]

Intergenerational trauma and the experience of past and present ableism, racism and sexism when interacting with systems and services generates distrust and causes reluctance to seek help when it is urgently needed.[64] Research we commissioned found that intersectional discrimination made people more likely to avoid justice, child protection, healthcare, education, employment and other services. This risk of experiencing racism and ableism, and consequent avoidance of government and other services, was greater for First Nations people with cognitive impairments and multiple conditions.[65]

2.4. Stigma, shame and a reluctance to identify

While First Nations cultures of inclusion have survived due to their strong foundation, racism and trauma work to undermine these cultural values and practices. As noted earlier, they weaken the very nature of kinship systems that are the cornerstone of First Nations society.[66]

A Torres Strait Islander community member who provides care to her sibling, who has a disability, explained the ways in which the understanding of the term had changed in her community:

> It's like people saying how do they say … the Torres Strait Islander people have the 'lore' as opposed to the 'law'. The law was put on us by white people. The same with disabled people. They lived without any stigma until that was put on by white people. They were just part of our family.[67]

Community members told us that after colonisation, First Nations children were 'sent away' from missions and other places because of their disability. Doctors and authorities often pressured parents and families to send their children with disability to institutions.[68] Ms Marmingee Hand told us her father still will not talk about the forcible removal of her sisters 'because it is too painful'.[69]

Ms Schwartz said her clients are happy to identify as First Nations peoples, but 'when we go to discuss disability, that is not something that is easily disclosed, and we have to unpack that and why is there still that shame element'.[70]

Organisations and workers in the Torres Strait spoke about the limited and, at times, outdated understanding and attitudes towards disability. We were told 'denial' around disability is commonplace:

> Sometimes parents don't want that support, they don't want to diagnose them, don't want to see them as different, say they're fine, there's nothing wrong, the teacher just needs to be harder and push them more to learn.[71]

We heard about parents in the Torres Strait keeping their children 'close' at home as a means of protecting them, and in some instances turning down disability assessments.[72] In remote parts of Western Australia, we were told about feelings of shame around drug and alcohol use and acquired brain injuries, particularly around FASD.[73] A service provider explained that while parents accepted that having a diagnosis was necessary to access supports for their child, the 'mum guilt' associated with FASD often resulted in reluctance to seek a diagnosis.[74]

Shame, guilt and lack of understanding about disability can result in stigma and exclusion within communities. This goes against traditional cultural practices of inclusion. Ms Narelle Reynolds said:

> Back then, before it was known, I think, about what Fragile X meant or how you could get it, I had comments such as, ‘Are you trying to tell me that some of my family is going to be spastic?’ You know, that was just a given word back then. And that caused me to move away from all my family because it was hurtful to me and my family, yes.[75]

2.5. The challenge and risk of diagnosis

There are multiple and sometimes conflicting forces that inform the reluctance of many First Nations families to seek and accept a disability diagnosis:

- cultures of inclusion that value people for who they are and discourage labelling
- intergenerational and direct trauma from prior experiences interacting with government systems and services
- a desire to avoid the compounding discrimination of racism and ableism
- stigma and shame about disability.

Dr Avery explained the effect of these multiple factors on reluctance to seek a diagnosis, using the example of FASD:

> So a medical model approach was, ‘You need to have a diagnosis’ … and there’s challenges of that. If you’re getting a diagnosis and you live in a remote community, there’s a whole range of health professionals that you need to consult: a paediatrician, a child psychologist ... But you might have the best diagnostic tool available, but the stigmas attached to, again, drinking and blame of the mother, or how the child might get labelled by a diagnosis, that’s a social thing, and those kind of things impact on whether they will come to the system in the first place. If they’re worried that they’re going to get blamed or stigmatised, they will avoid engaging with the system.[76]

At Public hearing 8, Commissioner Oscar AO described the real and justifiable fear felt by many First Nations mothers and families to seek a disability diagnosis and access disability supports and services:

> Having no choice but to access services that repeatedly pursues punitive action against families for having a child with complex health needs can cause extreme anxiety. It is for this reason that some Aboriginal and Torres Strait Islander people regard health care services, such as hospitals, as a last resort. In major cities, regional and remote locations across Australia, I heard repeated stories from women about being stereotyped, having their health concerns disregarded or minimised and having serious conditions misdiagnosed.[77]

The distrust that exists in First Nations communities runs deep. Ms Kim McRae from the Ngaanyatjarra Pitjantjatjara Yankunytjatjara Women's Council said:

> because of history, because of the history of children being removed from families on the Lands, the Stolen Generation, people have very negative experiences of having interaction with mainstream organisations and government organisations. And so they are reluctant to engage because of that history and that you need to build up a lot of trust with people.[78]

The impact of this long history of discriminatory treatment is a critical part of the explanation for the reluctance to label disability among First Nations people.[79] During Public hearing 8, Mr Weston described how, 'at times, community is deeply distrustful of medical labels given the past use of medical labels which were used to discriminate against Aboriginal and Torres Strait Islander people'.[80]

Evidence presented to the commission emphasised the limited cultural appropriateness of mainstream assessment processes for the diagnosis of disability among First Nations people.[81] Several witnesses gave evidence that culture is a significant factor in the presentation of psychosocial, cognitive and intellectual impairments.[82] They also said cultural bias, or lack of cultural competence, can undermine the reliability and validity of testing, assessment and diagnosis of disability.[83]

Dr Tracy Westerman AM, a Njamal woman of the Pilbara region who holds a PhD in clinical psychology, said First Nations people experience chronic misdiagnosis, over-diagnosis and under-diagnosis of disability, as a result of complex factors related to reluctance to identify, avoidance of diagnosis, cultural bias and lack of culturally appropriate mainstream assessment processes.[84] Following Public hearing 8, Counsel Assisting the Royal Commission submitted, and we agree, this affects the reliability of data and information obtained by governments and services systems on the disability status of First Nations people.[85]

In 2016, the Australian Psychological Society issued a formal apology to Aboriginal and Torres Strait Islander people for 'the inappropriate use of assessment techniques and procedures that have conveyed misleading and inaccurate messages about the abilities and capacities of Aboriginal and Torres Strait Islander participants'.[86] In issuing its formal apology to Aboriginal and Torres Strait Islander people, the society acknowledged 'psychology's role in contributing to the erosion of culture and to their mistreatment'.[87]

A lack of or inadequate diagnosis has a substantive impact upon the capacity of First Nations people with disability to access supports and services. Reluctance to seek diagnosis often results in First Nations people being unaware of the services and supports available to people with disability, including through the NDIS.[88]

Research we commissioned about parents with disability highlighted the issue. A service provider told researchers:

> Most parents that I've worked with have a pretty solid understanding of the disabilities that their children may have or of their own disabilities … Sometimes, they're just ignoring it because they don't want to be labelled as a parent with an autistic child, they don't want to put a label on their child because they think it's harmful. But something that I always like to reiterate to parents who are pushing this aside is that the label is not there to outcast your child or to outcast yourself, the label is there so you can access services, because you cannot access most services … without a diagnosis.[89]

A lack of or delayed diagnosis leads to inadequate, poorly tailored support, and makes it difficult to achieve positive outcomes.[90]

Even when aware of the NDIS and their rights to access support, First Nations people often struggle to satisfy eligibility requirements. Ms Jenny Bedford and Ms Cassie Atchison from Kimberley Aboriginal Medical Services told us how inadequate information about an individual's disability presents a barrier to accessing and obtaining the full benefits of the NDIS:

> There are often barriers to gathering the evidence of disability under the NDIS requirements of permanency and significance. Health records may not always show the persons disability, people don't always go to the clinic about their disability; and if a person does have a diagnosis they may not have evidence of the functional impacts to their day to day life.[91]

We address the implications of issues related to diagnosis in later chapters in this volume focused on access to services and support under the NDIS.

2.6. Social and emotional wellbeing

While reluctance to receive a disability diagnosis may reflect distrust about government services, First Nations people have expressed a strong desire for better access to appropriate, culturally safe services.[92] Ms Turner AM, CEO of NACCHO, said:

> Aboriginal and Torres Strait Islander peoples' access to health and disability services is mediated by the cultural appropriateness of those services. It is important that services and systems acknowledge the difference between the Aboriginal and Torres Strait Islander understanding of health and wellbeing and that of mainstream Australia. For Aboriginal and Torres Strait Islander people, health is understood as social and emotional wellbeing (SEWB), which connects the health of a person to the health of their family, kin, community, connection to Country, culture, spirituality, and ancestry.[93]

A First Nations understanding of health and social and emotional wellbeing encompasses the wellbeing of the whole community:

> The social and emotional wellbeing of Aboriginal people is strongly influenced by their connection to family, Elders, community, culture, country, and spirituality … SEWB is influenced by physical health, mental health, and the social determinants of health (for example, education, housing, employment, and economic engagement). Importantly for Aboriginal people, SEWB is also shaped by a collective history of colonisation and contemporary experiences of systemic racism and marginalisation.[94]

This approach to wellbeing challenges the tendency in non-Indigenous Australia to concentrate on individual wellbeing, largely disconnected from a person's place in their family and community.

The NDIS itself is largely built on an individualist model that does not always work well in a collectivist society, which needs holistic, family-centred services.[95] Kunmanara (Margaret) Smith, from the Ngaanyatjarra Pitjantjatjara Yankunytjatjara Women's Council, said:

> Family-centred is the way that we live in communities. People live in family groups, and people's identity is very much centred on their family and their position in the family … With individualised funding, yeah, it can be quite difficult, because that funding is focused on the person with the disability and not all the people around them. We – we work with the families because families provide the care out in community.[96]

The care-giving role is an important social function in First Nations communities, based on cultural and kinship obligations and responsibilities.[97] These pre-date Western systems of care-giving, which have become formalised through carer payments and the NDIS. A number of First Nations people with disability and their community organisations told us they received or provided support regardless of formal requirements or official payments.[98]

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15 Scott Avery, *Culture is inclusion: A narrative of Aboriginal and Torres Strait Islander people with disability*, First Peoples Disability Network Australia, 2018, p 5.

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17 Royal Commission community engagement, Tasmania, February 2021.

18 Speaker (name withheld), Royal Commission First Nations workshop, Sydney, August 2019.

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26 Exhibit 8-21, 'Statement of Candice Butler', 16 November 2020, at [19]; Exhibit 8-7, 'Statement of Professor Daryl Higgins', 12 November 2020, at [32]; Exhibit 8-24, 'Statement of Richard Weston', 23 November 2020, at [43]; Exhibit 8-6, 'Statement of Thelma Schwartz', 20 November 2020, at P-10 [28]; Exhibit 8-24.4, IND.0001.0004.0001, p 10.

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3. Ensuring cultural safety

Key points

- Connection with culture, Country, kin and community safeguards First Nations people with disability from violence, abuse, neglect and exploitation.
- First Nations people with disability experience cultural safety when their identity as First Nations people is understood, respected and celebrated along with their experiences and needs as a person with disability.
- First Nations people with disability often have to choose between a response that is accessible to them either in terms of their culture or their disability. This can lead to having to choose between culture or receiving disability support.
- First Nations people with disability will avoid supports or services if cultural safety is not assured. Denial of, or limited access to, culturally safe and inclusive services and supports constitutes neglect of First Nations people with disability.
- First Nations Community Controlled Organisations provide services that are culturally safe, trauma-informed and understanding of connection with culture, family and community.
- Government policy makers, and systems and service providers need to consider how First Nations peoples' specific circumstances shape the concept of cultural safety.

3.1. Introduction

> If we don't establish a trust and a cultural connection and create, you know, that cultural safety, then .... you can't work with our mob because they need that – to feel safe you need to know you're looking after them culturally.[1]

Respect for, and protection of, culture and identity are core components of the right to self-determination. It plays an important role in promoting health and wellbeing in First Nations communities, so having a strong identity is behaviour that is safeguarding a person, a family and a community. First Nations people with disability have told us that living for, through and with culture is central to their ability to live a good life. They have emphasised the importance of culture, Country, kin and community in safeguarding them from experiences of violence, abuse, neglect and exploitation.[2] This has included the importance of accessing First Nations services that are well versed in local protocols and languages, and employ First Nations staff.[3] This has been described to the Royal Commission as 'cultural safety'.

The right of First Nations people with disability to access and receive culturally safe disability services and supports has been a powerful theme throughout our inquiry. First Nations people with disability have identified a lack of culturally safe disability services and supports across almost every system they encounter. We have been told that this lack of cultural safety amounts to institutional neglect and a denial of the rights of First Nations people with disability.[4]

The Queensland Aboriginal and Torres Strait Islander Child Protection Peak suggested structural racism within service systems is a barrier to families seeking support.[5] First Nations people will avoid or delay accessing a service if they experience or perceive a lack of cultural safety.[6] The limited availability of First Nations disability service providers and culturally competent services has been identified as a driver of poorer outcomes for First Nations people with disability.[7] Culturally safe responses, including by the First Nations community-controlled sector, must also be informed by an improved understanding of disability.

This chapter sets out our understanding of cultural safety and experiences of both good and bad practice. Subsequent chapters discuss the changes required to ensure cultural safety for First Nations people with disability. These changes include the development of cultural safety standards and building the First Nations disability workforce to improve the disability expertise across the existing community-controlled sector. Volume 8, *Criminal justice and people with disability* makes recommendations to improve cultural safety in criminal justice settings.

3.2. What is cultural safety?

There are many aspects to what makes First Nations people feel culturally safe. Cultural safety is not a uniform concept. It varies between communities, locations and circumstances. The concept of cultural safety recognises, respects and nurtures First Nations people's unique cultural identities. We have been told cultural safety is defined by First Nations people with disability and through their interactions with services and systems.[8]

The National Agreement on Closing the Gap offers a definition of cultural safety centred on the person, their identity and their autonomy to determine whether they experience cultural safety:

> Cultural safety is about overcoming the power imbalances of places, people and policies that occur between the majority non-Indigenous position and the minority Aboriginal and Torres Strait Islander person so that there is no assault, challenge or denial of the Aboriginal and Torres Strait Islander person's identity, of who they are and what they need. Cultural safety is met through actions from the majority position which recognise, respect, and nurture the unique cultural identity of Aboriginal and Torres Strait Islander people. Only the Aboriginal and Torres Strait Islander person who is recipient of a service or interaction can determine whether it is culturally safe.[9]

In 2021, the Australian Government released the report *Keeping Our Kids Safe: Cultural Safety and the National Principles for Child Safe Organisations*. It describes cultural safety as:

> positive recognition and celebration of cultures. It is more than just the absence of racism or discrimination and more than ‘cultural awareness’ and ‘cultural sensitivity’. It empowers people and enables them to contribute and feel safe to be themselves.[10]

In the same year, the Australian Evaluation Society published a *First Nations Cultural Safety Framework* that described cultural safety as:

> an experience determined by First Nations peoples when they are in situations where their presence is welcomed and respected, their experiences are believed and validated, their cultures are centred and valued, their knowledges and skills are recognised and supported, their advice is listened to and acted upon, and they do not experience racism in any form.[11]

While the terms may vary, we understand cultural safety as an outcome that respects, supports and empowers the cultural rights, identity, values, beliefs and expectations of First Nations peoples while providing quality services that meet their needs.[12]

Cultural safety for First Nations people with disability

First Nations people with disability have stressed that cultural safety must encompass additional considerations in order to meet their specific needs.

The idea of cultural safety has its origins in health contexts, but these concepts do not necessarily respond to the needs and experiences of First Nations people with disability. We heard through community engagement and submissions that cultural safety has a particular meaning for First Nations people with disability. First Nations people with disability experience cultural safety when settings not only understand, respect and celebrate their identity as First Nations people but also understand, respect and celebrate their experiences and needs as a person with disability. First Nations people with disability have identified a need for existing culturally safe practices to meet their cultural and disability needs as a whole person, rather than providing for one but not the other.[13]

Many First Nations people with disability stressed the importance of accessing First Nations community-controlled services as their general preference. As we heard throughout Public hearing 25, ‘The operation of the NDIS for First Nations people with disability in remote and very remote communities’, this is the case particularly given the lack of disability services in remote and very remote locations.[14] However, in some instances, we were told that while these organisations are the provider of first choice, they sometimes are not set up to administer the NDIS, lack knowledge of the NDIS, or do not understand particular disabilities.[15]

As we outline in Chapter 8, structural reform that recognises the importance of enhancing the capacity of the existing community-controlled sector around disability is crucial. Given the barriers First Nations people face in accessing disability services, and their preference for using the community-controlled sector, this must be addressed as a matter of urgency.

Key characteristics of cultural safety

Cultural safety involves ‘overcoming the power imbalances of places, people and policies’, while recognising and nurturing the unique cultural identity of First Nations people.[16] Cultural safety has many characteristics, key among them including that it is:

- contextual – recognising and responding to intersectional needs and experiences
- built around trust – being relational, respectful and judgment free.

Ultimately, only the First Nations recipient of a service can determine whether it is culturally safe for them.[17]

Contextual

Evidence provided to the Royal Commission emphasised the need for government policy-makers and service providers to consider how First Nations peoples’ specific circumstances shape the concept of cultural safety.[18] What is considered culturally safe is determined by First Nations people with disability and is contextual in nature.[19]

What constitutes cultural safety differs for First Nations people with disability depending on their particular cultural and other needs, such as gender, age, First Nations language identity, LGBTIQA+ identity or geographic status. It may also vary depending on the nature of the harm they have experienced.

Research commissioned by the Royal Commission found cultural safety was central to whether First Nations women with disability disclosed family and domestic violence.[20] In school settings, the needs of a First Nations child who has a learning disability will differ between urban, rural and remote locations, and depending on the supports already available. For example, teachers in the Torres Strait told the Royal Commission that there were vast differences in the experiences of children with disability in places such as Thursday Island and on outer islands in the region, versus urban areas like Sydney.[21]

Gender also influences cultural safety. During our engagements, we heard about Supported Independent Living (SIL) accommodation housing First Nations men and women with disability in close proximity to one another, and how this was inappropriate. One First Nations service provider in the Northern Territory expressed concern about a guardian placing their client in such a situation, particularly when they had alternative resources to meet her needs. When the provider went to pick up their client, she told them she was the only female living with five men and that she did not want to stay. The provider was shocked that they would place a First Nations woman in SIL accommodation with five men.[22]

Trusted and free of judgment

First Nations people with disability told us that they need to feel safe, secure and free from stigma or shame in order to experience cultural safety.[23]

We were told First Nations peoples are more likely to access services they trust and feel are culturally safe, saying they experience better outcomes from such services.[24] A participant in the Wangkiny Yirra 'Speaking up' research project described cultural safety as involving practices such as 'come at it slowly' and 'build the relationship first'.[25] Other elements included there being 'people like me are here' and 'borrowed trust' (for example, knowing the Aboriginal medical service or other service is trusted by another trusted person within the kinship network).[26]

In Public hearing 25, we heard culturally safe services are those that employ local First Nations people to deliver services to their communities, and are trusted and respected by those communities.[27] Ms Turner AM, CEO of NACCHO, told us Aboriginal community-controlled health services 'provide embedded understanding and lived experience and are a culturally safe place for all community members to access primary healthcare and other services'.[28]

Witnesses identified the systemic power imbalance between First Nations communities and government systems.[29] This echoes the position of the Congress of Aboriginal and Torres Strait Islander Nurses and Midwives, who describe the 'cultural' in 'cultural safety' as not about cultural identity, ethnicity or traditions, but about the 'culture' of power.[30]

Cultural safety must encompass disability

First Nations people with disability emphasised that culturally safe responses include an understanding of disability and provide necessary supports. First Nations peak organisations stressed the need to build the disability expertise of the community-controlled sector.[31] This would better meet the needs of First Nations people with disability, who told us that they are unable to access supports that meet their cultural and disability needs.

First Nations people with disability often have to choose between a response that is accessible either in terms of their culture or their disability.[32] Mr Griffis, CEO of FPDN, described the lack of responses that meet intersectional needs:

> Some examples of how that plays out practically, which again demonstrates how systems don't know how to address intersectional discrimination, it's not unusual for us to get a call from a parent, say, when they are enrolling a young Aboriginal person with disability at school and they will often ask us the question, 'Should I tick the disability box or the Aboriginal box when I enrol my child at school?' What they are saying there sometimes is, 'What will get me the best potential resources or support for my child?' … So the thing that is of course silly about that is that they have both identities.[33]

During a Sydney workshop, a senior man with disability told the Royal Commission about the frustration of engaging with disability service providers who lack the cultural awareness and disability training to provide culturally safe services to First Nations people with disability.[34] This was also described by a Deaf community member, who outlined the challenges of services meeting client needs:

> You go to an organisation who is Deaf, they don't have the Aboriginal lens, you go to Aboriginal organisation, they know nothing about deafness. Why can't we go to one place? There are multiple identities, why can't we go to one organisation, and that person [who] is left lacking, this person – whoever they are - we deserve to have a one stop shop.[35]

Recent research identified the lack of cultural safety experienced by Deaf and hard of hearing groups, particularly in relation to their understanding of and access to the NDIS.[36] Despite high rates of hearing loss within First Nations communities, the research contends that major blueprints such as the NDIS Aboriginal and Torres Strait Islander Engagement Strategy are 'silent' on the views and experiences of people who identify as Deaf or hard of hearing.[37]

A lack of cultural safety is neglect of First Nations people with disability

Denial of, or limited access to, safe, inclusive, quality services and supports results in continued neglect of First Nations people with disability. As set out in Volume 3, *Nature and extent of violence, abuse, neglect and exploitation*, the Royal Commission's definition of 'neglect' includes the exclusion of a person with disability from accessing and participating in a service available to other members of the community. This also encompasses people with disability being excluded from accessing culturally safe and appropriate services.

We consider this exclusion amounts to the systemic neglect of First Nations people with disability by governments, institutions and organisations responsible for providing services. While this systemic neglect is a problem in itself, we also consider it creates environments more likely to encourage violence, abuse and exploitation of First Nations people with disability.

Cultural safety is essential for First Nations people with disability to access services and support. The Victorian Aboriginal Community Controlled Childcare Agency (VACCA) told us:

> The current medical model that requires a rigid assessment to obtain a diagnosis of a disability were not designed with Aboriginal people in mind. The medicalised model significantly lacks cultural safety elements and limits Aboriginal disabled people from accessing the supports they need early. We also know that much of the disability or impairment among Aboriginal children is invisible. We firmly believe that if access to costly and time-consuming assessments are not changed, this will continue to be a failure of the NDIA and the NDIS to understand the needs of disabled Australians.[38]

The Uniting Church in Australia and the Uniting Aboriginal and Islander Christian Congress told us, 'navigating systems that are not culturally appropriate or culturally inclusive adds yet another layer of disadvantage' for First Nations people with disability.[39] Mental Health Victoria said the challenges in maintaining cultural identity within a dominant and at times antagonistic culture can lead to acculturative stress.[40]

Culture and inclusion

Throughout our inquiry, we heard how culture is a source of strength, resilience, happiness, identity and confidence for First Nations people. It has a powerful, positive impact on health and wellbeing.[41] First Nations people with disability have described the importance and centrality of culture to their lives and their desire to live a good life.[42] We have been told that First Nations people with disability turn to their culture as a source of strength that assists their sense of belonging.[43] Accessing culture, being on Country and feeling safe to express identity is integral to who they are. We heard that recognising the significance of culture is considered good practice in all service settings.[44]

This reflects the holistic concept of health for First Nations people that reflects whole-of-life experiences and incorporates social and emotional wellbeing. Dr Avery describes the whole-of-life view of disability taken by First Nations communities. It is a view that incorporates the centrality of family, community and connectedness through culture.[45] He describes this as a 'culture of inclusion', which mitigates the impacts of intersectional inequality.[46] First Nations organisations and peak bodies have described how this is tied to the communities' holistic view of the physical, cultural and spiritual components of health and wellbeing of their members with disability.[47]

The Northern Territory Public Guardian, Ms Beth Walker, told us that the importance of culture, kinship and Country cannot be overstated.[48] She said the failure to acknowledge the importance of these connections contributes to poorer quality of life for First Nations people with disability.[49]

During Public hearing 25, we were told that First Nations people with disability want the design and delivery of disability programs and services to reflect and embed First Nations self-determination.[50] In Public hearing 4, 'Health care and services for people with cognitive disability', Ms Narelle Reynolds described her role in her community, where she assists First Nations people with disability to connect with health services.[51] She said, sometimes 'black fellas have to interpret for each other'.[52] Ms Reynolds also told us about her role as an advocate and intermediary between service providers. She said, 'I will offer my services free to help them understand what it means to be Aboriginal, and what it means for my sons to have a disability'.[53]

In relation to school experiences, Dr Avery's research demonstrates that First Nations students and families want the education system to be inclusive of their culture as well as their disability.[54] This was supported by recent research studying the experiences of autism in First Nations communities. Women participating in the study wanted schools to 'bend to Aboriginal ways' and understand that 'families would drop anything for their culture'.[55] The Queensland Aboriginal and Torres Strait Islander Child Protection Peak similarly noted the preservation and strengthening of First Nations cultural identity must be at the cornerstone of disability support for children and their families.[56]

Witnesses at Public hearing 11, 'The experiences of people with cognitive disability in the criminal justice system', gave evidence about the importance of culturally safe and competent services for First Nations people with cognitive disability engaging with the criminal justice system. For example, Ms Cheryl Axleby, who is a Narungga woman and CEO of the Aboriginal Legal Rights Movement in Australia, expressed the view that:

> Culturally safe services are essential for effective engagement, communication, delivery of services and the attainment of successful outcomes as a result of cultural understanding of the unique issues which impact upon Aboriginal and Torres Strait Islander people with disability.[57]

3.3. Challenges and consequences of a lack of culturally safe and appropriate services

We have consistently heard about the failure of both disability and mainstream services to understand the central role of culture in the lives of First Nations people with disability.[58] The lack of culturally safe disability services is a major barrier to First Nations people with disability receiving the supports they need.[59] FPDN told us that service systems continue to display cultural biases in their operations and fail to see the strengths of First Nations people with disability and communities.[60] This results in a lack trust in service providers.[61]

We heard how First Nations people with disability are often forced to choose between their First Nations identity and culture, and their disability.[62] NACCHO told us that 'tick box' options can lead to First Nations people having to choose between their culture and receiving care for their disability.[63]

First Nations people with disability have told us about culturally inappropriate service delivery and care, a lack or absence of cultural safety and capacity, and of being denied access to Country and culture. We have been told of the failure of mainstream services to understand the lives and cultures of First Nations people living in remote parts of Australia.[64]

Culturally unsafe settings

At Public hearing 25, Ms Turner AM told the Royal Commission that a failure to provide culturally safe services can result in further harm. It:

> may also give rise to gender, age and other cultural misunderstandings which can result in Aboriginal and Torres Strait Islander people experiencing offence or trauma. It can mean the perpetuation of systemic and/or interpersonal racism. We know this impacts the mental health of Aboriginal and Torres Strait Islander people and contributes to poorer health outcomes as detailed above.[65]

Public hearing 16, 'First Nations children with disability in out-of-home care', and Public hearing 27, 'Conditions in detention in the criminal justice system', raised the inadequacy of cultural safety in relation to the experiences of First Nations children with disability in detention settings in Western Australia and the Northern Territory. This is further explored in Volume 8, *Criminal justice and people with disability*.

Family Matters representatives collectively commented that:

> secure care is not culturally appropriate for Aboriginal and Torres Strait Islander children. Family, community and culture sit at the centre of healing for Aboriginal and Torres Strait Islander children, yet young people in secure care are often cut off from this.[66]

The cultural safety of child welfare settings has also been raised with the Royal Commission. In Public hearing 8, ‘The experiences of First Nations people with disability and their families in contact with child protection systems’, we heard evidence from First Nations mothers with disability that child protection agencies did not offer culturally safe programs or supports to address safety concerns.[67]

We have been told that there is a lack of cultural safety in the delivery of education programs and the provision of supports and reasonable adjustments.[68] A private session participant told us:

> It doesn’t endear our kids with disability to want to learn because they’re just trying to make it through the day, they’re just trying to live in a world that they don’t fit into.[69]

The lack of culturally safe services in correctional centres also emerged as a theme raised by First Nations prisoners with disability, advocate organisations and services providers. It is detailed in research and multiple past inquiries.[70] A First Nations woman with disability in prison in Queensland told us, ‘we don’t want to always go the white fella way, we need the Indigenous way’.[71] We were told about the experiences of a First Nations woman from a remote community with an undiagnosed disability that affected her ability to speak or communicate. When she appeared in court, ‘they couldn’t even say her name, no interpreter, she couldn’t talk to them’.[72]

3.4. Good practice in cultural safety

The Royal Commission heard evidence from a broad range of First Nations organisations about how they are ensuring cultural safety for First Nations people with disability. These approaches are built on co-design and power-sharing practices, alongside a genuine intent to listen to First Nations people with disability.[73] We repeatedly heard about the importance of taking time to ensure the best outcomes are achieved.

In Public hearing 11, Ms Christine May gave evidence about the Cultural Healing Program run through Queensland Health, which runs its own intakes, assessments and case management. It also has a part-time psychiatrist attached to the team.[74] She told us of the importance of continuity of care, a model of service delivery ‘which is culturally correct and the way that we should be working’.[75] In Public hearing 8, we heard from ‘Ann’ and how the Cultural Healing Program helped her maintain contact with her son in out-of-home care.[76]

> They were just amazing. They really helped me emotionally. They were, like, just telling me that I can do it, just keep going, and, you know, they linked me in with services that would actually help, not just weigh me down … they knew our family, they knew our story from the start.[77]

Evidence was given about the Kin Connect Program, which supports First Nations peoples' need for community, culture and Country.[78] The program supports clients who can no longer live in their remote community to maintain cultural connection by returning to their Country, family and community for a short time. This experience increases clients' wellbeing, and their community and cultural participation.[79]

Aboriginal and Torres Strait Islander Social Justice Commissioner June Oscar AO provided evidence on the Marninwarntikura Women's Resource Centre's 'on Country' programs. These programs allow family groups, women and children, and artists to spend time on-Country engaging in a range of cultural, educational and healing activities.[80] She described how important on-Country programs are for children and families with disability who are able to relax in a calmer and more engaging environment.[81]

Culture-based on-Country programs that harness Indigenous knowledge and are adequately resourced are an essential part of disability supports:

> Aboriginal and Torres Strait Islander peoples have long been using our cultural practices – of being on-country, singing, dancing and learning our songs and Law – as methods of healing … Our cultural practices can be used as forms of therapy that can greatly enhance the cultural safety and effectiveness of disability supports and programs for First Nations people.[82]

The Royal Commission heard about the Balit Narrum best practice model for First Nations support coordination.[83] It is based on a holistic practice and grounded in culture, community and collective identity and cultural safety. This holistic practice empowers a person to exercise their individual authority over their life:

> The person is at the centre. Surrounding them is their culture, which encompasses their families and communities and perhaps as well some of their past experiences. The services they may receive encircle both the person and their culture in recognition that every service must intervene in a way that acknowledges, recognises, and addresses culture in a safe and respectful way. In this model, the outcomes that are sought also go beyond the person.[84]

Our commissioned research also provided examples of women having positive experiences of culturally safe practice within mainstream services.[85] These involved clinicians, usually general practitioners, building strong relationships, incorporating informal yarning into healthcare consultations, and treating women with respect:

> My doctor is a real good doctor. He's really good. I can talk to him about anything. Doc has known me for a long time. Him and Dr [name], that's the main two I speak to, that I can talk and say anything. I can swear and laugh and cry. They'll have a laugh with me.[86]

The role of First Nations Community Controlled Organisations

First Nations people with disability prefer Aboriginal Community Controlled Organisations (ACCOs) where their cultural safety is assured.[87] In Public Hearing 25, Ms Jenny Bedford told the Royal Commission that the ACCO and ACCHO model is person and family-centred, and underpinned strongly by cultural safety 'because culture is our life'.[88] Visiting an ACCO or ACCHO can provide a unique respite, in an environment where First Nations people feel safe and can place their trust in the worker and service.[89]

The Royal Commission heard evidence about the breadth of work undertaken by Aboriginal Community Controlled Health Organisations (ACCHOs):

> ACCHOs are more than just another health service. We put Aboriginal health into Aboriginal hands. And there are some key domains within the model that talk about, you know, what are the things that make our community feel good and feel healthy. And they are things like, you know, culture, family, community … it's not just about the physical health, it's about our spiritual health and our emotional health, and it's underpinned very strongly by cultural safety, because culture is our life.[90]

In Public hearing 25, Ms Turner AM described how cultural respect and cultural safety can be better guaranteed by ACCHOs, which are highly visible and trusted in First Nations communities.[91] They understand lived experience and are free from stigma and shame.[92] Ms Kim McRae gave evidence about the role of local organisations:

> They know about culture. They know about language. It just completely makes sense to just work with the local organisations to try and develop supports for people with disability.[93]

In Public hearing 11, we heard about the ways in which ACCOs deliver culturally safe services. Ms Cheryl Axleby gave evidence that ACCOs are 'really engaging with families and communities' to foster 'a greater connection' through 'connecting with people in the community that you know are family'.[94] Another witness, Mr Lewis Shillito, described how ACCOs engage 'with that person in need' to build a rapport and relationship 'where they trust you enough to allow you to deliver whatever service it is you are trying to deliver'.[95]

In Public hearing 17, 'The experience of women and girls with disability with a particular focus on family, domestic and sexual violence', we heard about the need to build and grow ACCOs. Ms Thelma Schwartz, Principal Legal Officer from the Queensland Indigenous Family Violence Legal Service, told us 'we have the skill set, we have the knowledge. We know how to deal and respond in a culturally safe manner for our people's problems'.[96] We heard community members with disability are safest in the hands of ACCOs and First Nations staff:

> This is due to shared values, trauma-informed approaches and understanding of Culture, family, Community and respecting the holistic nature of the individual. It is also because Culture is the key protective factor for Aboriginal people with disability, enabling them to remain included and supported.[97]

The Wangkiny Yirra ‘Speaking up’ research project reported on aspects of cultural safety in the ACCO sector and its importance when working with First Nations clients with disability. In some cases, tension exists between cultural safety and mainstream services due to the different world views of disability and ways of working:

> The thing is, is that’s what we want; we want Aboriginal people working with Aboriginal people. We want to build that trust and the only way you can build trust with Aboriginal people is by getting them to work with Aboriginal people.[98]

However, cultural safety is not solely the responsibility of First Nations organisations. It is the responsibility of all government agencies and mainstream service providers who provide supports and services to First Nations people with disability.

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4. The experiences of First Nations people with disability

Key points

- The prevalence of disability is much higher in First Nations populations than in the general population.
- Approximately one in five (72,700) First Nations children aged under 18 have disability, compared with one in 12 children in the general population.
- Safe, including culturally safe, and inclusive schools are a critical building block helping First Nations children to avoid interaction with justice and child protection systems, and to enter adulthood free from violence, abuse, neglect and exploitation.
- Many First Nations students with disability face bullying at school, and are not able to access culturally safe supports or resources they need to flourish.
- We heard that First Nations students experience much higher rates of ‘exclusionary discipline’ than non-Indigenous children.
- First Nations people with disability experience poorer health outcomes than non-Indigenous people with disability. Barriers to quality healthcare include systemic racism and the lack of culturally safe health services.
- Bias around race and disability can lead to ‘diagnostic overshadowing’.
- We heard the lack of culturally safe assessment tools contributes to the underdiagnosis or misdiagnosis of disability among First Nations people. A sophisticated approach is required in which all parts of a healthcare system come together to accept responsibility for attaining improvement in health outcomes.
- First Nations people with disability are disproportionately affected by family violence. They report extreme, prolonged violence from multiple intimate partners throughout their lives.
- Barriers to reporting and receiving supports include fear of child protection, loss of home and community, and lack of culturally safe services.

4.1. Introduction

First Nations people with disability shared their experiences of violence, abuse, neglect and exploitation with the Royal Commission. Their stories demonstrate that incidences of maltreatment are not isolated events in their lives. This has contributed to our understanding that these experiences occur in many forms across different settings and life stages. The continued marginalisation of First Nations people generally in Australian society is amplified for those with disability.

Violence, abuse, neglect and exploitation may occur in interpersonal relationships – between family and kin, in community, through professional contact, and with peers at school or work. As well as interpersonal violence and abuse, First Nations people with disability face barriers to and exclusion from health and education systems and settings.

This chapter sets out what we know about the rates of First Nations people with disability and the violence and abuse they experience. This data should be viewed within the life course framework. This perspective helps us understand how relational, cultural, systemic and societal structures influence the experiences of First Nations people with disability. Each life stage can present its own risks and challenges, and impact the trajectory of a person's life.

This chapter discusses the experiences of First Nations people with disability in the context of:

- interpersonal violence and abuse in family and kinship relationships
- exclusion, neglect and unsafe cultural practices in health and education settings and services.

4.2. Nature and extent of interpersonal violence and abuse

This section provides details on the number of First Nations people with disability in Australia. It includes the types and 'severity' of their disability, and what we know from statistical data about their experiences of interpersonal violence and abuse.

Volume 3*, Nature and extent of violence, abuse, neglect and exploitation* sets out in more detail data on First Nations people with disability and rates of violence and abuse.

As we have explained, for many First Nations people, interpersonal violence and abuse are inextricably related to the ongoing impacts of colonisation, intergenerational trauma and structural racism.[1] These impacts are multiplied for people with disability, who face additional disadvantage based on their disability. First Nations people with disability are a diverse group and their experiences vary substantially. These variations are not always clearly evident based on the data alone.

First Nations people with disability

The data presented below shows the high prevalence of disability among First Nations communities, and demonstrates the elevated rates of interpersonal violence and abuse experienced by First Nations people with disability. The rates of interpersonal violence and abuse experienced by First Nations women with disability are higher still. Details about these datasets and their parameters are set out in Volume 3, *Nature and extent of violence, abuse, neglect and exploitation.*

The Australian Bureau of Statistics *National Aboriginal and Torres Strait Islander Health Survey 2018–19* (*NATSIHS*) is the most reliable recent source on the number of First Nations people with disability. National figures are likely underestimates of the number of First Nations people with disability in Australia. As discussed in Chapter 2, First Nations people may not self-identify and report as having disability for cultural reasons.

According to *NATSIHS*, around 35 per cent (274,400) of First Nations people under 65 years of age have a disability.[2] This percentage is nearly three times higher than the percentage of people with disability in the general population (12 per cent).[3]

Around 202,200 First Nations adults aged between 18 and 64 have disability, representing almost half of all First Nations adults (45 per cent), and 66 per cent of First Nations people with disability (see Table 9.1). Nearly four out of every five (79 per cent) older First Nations people aged 65 and over have disability.[4]

Table 9.1: Number and percentage of First Nations people with disability by age group, 2018 –19

Age group	Number of First Nations people with disability ('000')	Of First Nations people, percentage with disability	Of First Nations people with disability, percentage by age group
Children (aged under 18)	72.7	22.2%	23.8%
Adults (aged 18–64)	202.2	45.3%	66.1%
Older adults (65+)	31.4	79.3%	10.3%
Total	**306.1**	**37.6%**	**100.0%**

Note: The number of people with disability in each age group do not add up to the total people with disability because the Australian Bureau of Statistics changes some numbers to protect the confidentiality of people completing the survey.

Source: Australian Bureau of Statistics, National Aboriginal and Torres Strait Islander Health Survey, (2019).

The proportions of men and women aged 16 to 64 with disability are similar, at around 45 per cent.[5] Almost half (45 per cent) of all First Nations adults (between 18 and 64 years of age) have disability. Of First Nations adults with disability, around 19 per cent have profound or severe disability.[6]

Table 9.2 shows the types of disability for First Nations adults aged 18 to 64:[7]

- the most common disability type is physical disability, with around 28 per cent of First Nations adults having physical disability
- 21 per cent have sensory disability
- around 12 per cent have psychological disability.

Table 9.2: Number and percentage of First Nations adults aged 18-64 with disability by disability type, 2018-19

Disability type	Number of First Nations adults with disability ('000')	Of all First Nations adults, percentage by disability type
Sensory	93.0	20.8%
Intellectual	38.6	8.6%
Physical	127.0	28.4%
Psychological	51.3	11.5%
Head injury, stroke or acquired brain injury	7.5	1.7%
Other	58.3	13.1%
Total	**202.2**	**45.3%**

Note: People can experience more than one disability type at a time. This is why the sum of the number of people in each disability type does not equal the total number of people with disability, or why the summed percentage of people in each disability type may exceed the total percentage.

Source: Australian Bureau of Statistics, National Aboriginal and Torres Strait Islander Health Survey, (2019).

First Nations children with disability

Around 72,700 First Nations children (aged under 18) live with disability, which is more than one in five First Nations children (22 per cent).[8] This compares with a figure of around one in 12 children (8.3 per cent) in the general population.[9]

Children account for almost one-quarter (24 per cent) of all First Nations people with disability.[10] The percentage of First Nations children with disability is higher for boys (26 per cent) than for girls (18 per cent).[11] Around 20,900 First Nations children have profound or severe disability, which is around 29 per cent of all First Nations children with disability, and 6.4 per cent of all First Nations children.[12]

The most common disability type among First Nations children is sensory disability (see Table 9.3) – nearly 40,000 children (12 per cent).[13] Around 8.8 per cent of First Nations children have intellectual disability and around 4.7 per cent have physical disability.

Table 9.3: Number and percentage of First Nations children with disability by disability type, 2018–19

Disability type	Number of First Nations children with disability ('000')	Of all First Nations children, percentage by disability type
Sensory	38.7	11.8%
Intellectual	29.0	8.8%
Physical	15.5	4.7%
Psychological	13.4	4.1%
Head injury, stroke or acquired brain injury	0.7[a]	0.2%[a]
Other	13.2	4.0%
Total	**72.7**	**22.2%**

'a' indicates a moderate margin of error. Estimate should be used with caution and interpreted as 'indicative'.

Note: People can experience more than one disability type at a time. This is why the sum of the number of people in each disability type does not equal the total number of people with disability, or why the summed percentage of people in each disability type may exceed the total percentage.

Source: Australian Bureau of Statistics, National Aboriginal and Torres Strait Islander Health Survey, (2019).

Rates of interpersonal violence and abuse

National data demonstrates that First Nations people with disability experience high rates of interpersonal violence and abuse. Most of the data we have about rates of violence and abuse is from the *NATSIHS* and the New South Wales Bureau of Crime Statistics and Research (BOCSAR). Details about these datasets and their parameters are set out in Volume 3, *Nature and extent of violence, abuse, neglect and exploitation.*

NATSIHS survey results are considered representative of First Nations people living in both remote and non-remote areas.[14] However, the data should be interpreted with the caveat that First Nations peoples are diverse, and can have vastly different experiences across communities and locations.

Physical harm or threats of harm

In the *NATSIHS*, the Australian Bureau of Statistics defines physical harm as being harmed by someone else on purpose. First Nations people with disability experience high rates of physical harm compared with those without disability, according to data drawn from *NATSIHS*.[15]

First Nations people with disability aged 15 to 64 are more likely to experience physical harm or threats of physical harm in the previous 12 months (22 per cent) than First Nations people without disability (12 per cent).[16] They are also more likely to experience multiple incidents of physical harm than other First Nations people.[17] Of those who experienced physical harm, 70 per cent of people with disability experienced more than one incident, compared with 48 per cent of people without disability.[18]

First Nations women with disability

A study by BOCSAR shows First Nations people with disability in New South Wales are subjected to high rates of violent crime.[19] For women with disability, these rates are even higher.[20] In New South Wales, First Nations women with disability were at least twice as likely as non-First Nations people with disability to be victims of violent crime.[21] The rates for experiencing any crime were highest for First Nations women with disability aged 15 and over (34 per cent).

In comparison, the rates for experiencing any crime were:[22]

- 29 per cent for First Nations men with disability
- 16 per cent for non-First Nations women and men with disability.

Family and domestic violence

First Nations women are at heightened risk of family and domestic violence. The intimate partners of First Nations women with disability can be Indigenous and non-Indigenous. Data collected by the Australian Institute of Health and Welfare (AIHW) found that in 2016–17, rates of hospitalisation due to family violence were 34 times higher for First Nations women aged 15 and over than non-Indigenous women, and First Nations men were 27 times as likely to be hospitalised as non-Indigenous men. For First Nations women, a spouse or domestic partner was the perpetrator in 62 per cent of cases, whereas for men, the perpetrator was most likely to be another family member.[23]

This risk of family violence is compounded for First Nations women with disability, as demonstrated in several national and state-based surveys. During the onset of the COVID-19 pandemic, the Australian Institute of Criminology found that compared to non-Indigenous women with disability, they were 2.7 times as likely to experience physical or sexual violence in the first three months of the pandemic (42 per cent and 16 per cent respectively), and almost three times as likely to experience coercive control in family and domestic relationships (52 per cent and 18 per cent respectively).[24]

Data analysed by BOCSAR shows First Nations women with disability experience the highest rates of crime related to domestic violence when compared to First Nations men and non-Indigenous men and women with disability.[25] Nineteen per cent of First Nations women aged 15 and over experienced domestic violence related crime,[26] compared with 8.6 per cent of First Nations men, and 5 per cent of non-First Nations women.[27]

The 2018–2019 *NATSIHS* found:

- First Nations women with disability aged 15 to 64 are more than twice as likely than First Nations men with disability to report that their current or previous intimate partner was the perpetrator of physical harm against them in the previous 12 months (53 per cent and 25 per cent, respectively).[28] This was the most commonly reported perpetrator for First Nations women with disability and was higher than for First Nations women without disability (49 per cent).[29]
- For First Nations men with disability aged 15 to 64, the most commonly reported perpetrator of harm in the previous 12 months was a parent, child, sibling or other family member (excluding partners) (39 per cent).[30]

First Nations children are much more likely than non-Indigenous children to be exposed to family violence, and this is even higher for First Nations children with disability. Thirty-six per cent of First Nations children with disability had a mother hospitalised as a result of family violence compared with 26 per cent of First Nations children in general and 3 per cent of non-Indigenous children.[31]

Rates of harm by disability type

The *NATSIHS* survey shows that First Nations people with head injury, stroke or brain damage experience the highest rates of physical harm or threat of physical harm of all First Nations people with disability. However, rates of physical harm among all reported disability types are substantially higher than among First Nations people without disability. According to *NATSIHS,* for people aged 15 to 64:[32]

- More than one-quarter of First Nations men with psychological disability (29 per cent) and 26 per cent of First Nations men with intellectual disability experienced physical harm or threat in the previous 12 months.
- For First Nations women, 35 per cent of women with head injury, stroke or brain damage, 27 per cent with intellectual disability and 26 per cent with psychological disability experienced physical harm or threat in the previous 12 months.
- Among both women and men, rates were slightly lower for people with physical disability (25 per cent) or sight, hearing or speech disability (23 per cent).

4.3. Across the life course

We use a life course approach to help us understand how First Nations people with disability experience violence, abuse, neglect and exploitation at different stages of their lives, and how it impacts their life pathways and outcomes. These experiences are often inter-related, as the effects of maltreatment accumulate and increase the risk of further harm.

The life course framework also considers the heightened impacts of experiences of First Nations people with disability as they are exposed to multi-layered disadvantage throughout various life stages.[33] This section considers some key areas of abuse, both individual and collective, that shape the lives of First Nations people with disability. The life course framework is set out in more detail in Volume 3, *Nature and extent of violence, abuse, neglect and exploitation.*

First Nations considerations in the life course framework

As discussed in Chapters 1 and 2, the impact of colonisation places a burden on First Nations people with disability from the time they are born. For many, it is important to see the life course of the individual in the context of intergenerational trauma, which can influence the life course of First Nations children with disability. This results in multiple disadvantages as they interact with different systems and settings throughout their life.[34]

For example, in 2014–15 more than two-thirds (67 per cent) of the Stolen Generations lived with disability or a restrictive long-term condition.[35] This group experiences much poorer social and health outcomes and a higher incidence of violence and abuse (compared with First Nations people who report neither being removed themselves from their own families, nor having any relatives removed).[36] In Public hearing 17, 'The experience of women and girls with disability with a particular focus on family, domestic and sexual violence', 'Etana' described how the removal of her grandparents during the Stolen Generations contributed to a cycle of inter-generational trauma and violence.[37] Etana's story is set out in further detail later in this chapter.

In one workshop, a Latje Latje man said he cycled through foster homes in Melbourne, far from the life he 'should have been living'.[38] His experiences of violence and abuse had 'lifelong ramifications' and helped explain the reluctance of First Nations people with disability to engage with services.[39]

Life-stage analysis

In his *Culture is inclusion* report, Dr Scott Avery identified common issues experienced by First Nations people with disability in response to their First Nations status and their disability. Dr Avery mapped these influences across the life course from pre-birth to older years, illustrated in Table 9.4.[40] The Royal Commission uses this framework to understand the experiences of First Nations people with disability across the life course.

Table 9.4. Issues facing First Nations people with disability and people with disability in different settings across their life course.[41]

Life-stage aspect	Aboriginal and Torres Strait Islander	Disability
Peri-Natal	Low awareness of disability. Environmental factors, increased likelihood of low birth-weight	Low birth weight and environmental factors in developmental disability
Early childhood	Low awareness of disability. Exposure to trauma. Increased likelihood of OOHC – off-country, unstable home setting	Disability assessments aren't carried out to the extent that they need to be
Schooling years	Low awareness of disability. "Bad black kid syndrome" – punitive schooling over supported disability	Undiagnosed and unsupported disability
Young people	Less likely to secure employment. Increased likelihood of police contact	Less likely to secure employment. Communication impairments, reduced capacity to negotiate conflict
Justice	Denial of rights – over incarceration	Denial of rights – indefinite detention and fitness to plead for people with cognitive and psychiatric disability
Health	Subconscious bias – institutional racism	Subconscious bias – diagnostic overshadowing
Ageing	Reduced life expectancy. Disability happens earlier in life and with more co-morbidities	Inadequate public infrastructure especially in remote communities

First Nations people with disability told us about violence, abuse, neglect and exploitation they experience at every stage of life. The examples given below are not exhaustive and should not be viewed in isolation, but illustrate the forms of maltreatment they may be exposed to at various points. These examples also demonstrate the interconnectedness of each life stage, as experiences of violence or abuse in one stage go on to affect outcomes in other stages. Together they contribute to the overall trajectory of individual lives and communities.

Perinatal and early childhood

> There was a lot of alcohol and drugs, a lot of criminal activity going on around me. A lot of violence. It wasn't very good for a kid … [I] had a hard time as a young fella.[42]

During community engagements, members spoke about the devastating impact of alcohol use in pregnancy, particularly children being born with fetal alcohol spectrum disorder (FASD). FASD is a neurodevelopmental disorder, which is a lifelong condition.[43] It is caused by prenatal exposure to alcohol. Community members reported feeling despair over the intergenerational nature of the disorder and the way this affects the life of the child and their family and community. A community health worker told the Commission 'we've got FASD kids having FASD kids here now'.[44] Barriers to accessing supports for diagnosis and treatment for FASD and other disabilities are discussed later in this chapter and in Volume 6, *Enabling autonomy and access.*

Community engagement participants spoke about a lack of services for FASD diagnosis and treatment in remote communities. We were told some parents and child protection departments delayed or resisted obtaining a formal diagnosis to avoid associated stigma or financial costs. Aboriginal Community Controlled Organisations said they often step in to provide essential supports to young First Nations people and their families with FASD. For example, we were told that the Central Australian Aboriginal Congress established the Child and Youth Assessment and Treatment Service team in 2018 to provide best-practice early detection and treatment of neurodevelopmental conditions, such as FASD, attention-deficit hyperactivity disorder (ADHD) and Autism Spectrum Disorder.[45] This type of assessment and treatment service did not previously exist in Alice Springs.[46]

Danila Dilba Health Service provides primary health care and community services in the Yilli Rreung (greater Darwin) region of the Northern Territory. It stressed the need for better funding to provide culturally appropriate supports, including through the NDIS. Even with a formal diagnosis, a young person can wait up to two-and-a-half years to access therapeutic supports under the NDIS.[47] During a community engagement, we heard that despite being in more need of supports, children with FASD 'get less' and the gap only widens as they grow older.[48]

For example, one in five children born in 2002–03 in Fitzroy Crossing were documented as having any diagnosis on the FASD spectrum.[49] Despite the known prevalence, community members said there had been little positive change to diagnose and treat FASD. One community engagement participant said that Fitzroy Crossing was the only community in the country where the true prevalence of FASD was actually known, and they still could not get a diagnosis.[50]

Government intervention and barriers to accessing disability supports

First Nations people may be reluctant to engage with disability support services and other essential services because they fear intervention from government authorities and the potential for child removal. Fears of children being taken away in cars, in a way not dissimilar to practices used during the Stolen Generations, were raised during our community engagements.[51] Delaying or avoiding access to disability supports can impact developmental, health and educational outcomes and in turn increase the risk of contact with child protection authorities.

A lack of disability supports and services for young people, particularly in remote areas, means that some families may be faced with the difficult decision of having to relinquish the care of their child. A community engagement participant from remote Western Australia spoke about the strain that inadequate support services can put on a family.[52] Similarly an employee at an Aboriginal Community Controlled Organisation (ACCO) in the Northern Territory described the experience of one of her clients, and her client's son who has cerebral palsy. This client tried to keep her son at home and in the community for as long as possible.[53] As he got bigger and heavier, it became harder for his mother to provide his personal care. He ended up having to move away from his family to the nearest service centre.[54] She said that whenever his mother and grandmother come to visit him, he 'picks up'.[55]

Schooling years

First Nations children and young people with disability experience various forms of maltreatment at school, including bullying, exclusionary discipline, restrictive practices, and exclusion through low expectations. These are set out in more detail later in this chapter and in Volume 7, *Inclusive education, employment and housing.* These experiences have impacts on their education and longer-term social and economic participation.

Participants in the Wangkiny Yirra 'Speaking up' research project reported being bullied extensively by other students at school, but were often expelled themselves.[56] Some felt depressed and reluctant to go to school because their experiences were not being addressed.[57] As one student explained:

> Every time I'd go back to school, they would bully me and tell me that I deserved it and all this and that … Yeah, really nasty. I didn't really have any friends there and I felt like I was alone and so every time recess and break would come, I would always go and sit in the toilet because I didn't want to be seen from other kids.[58]

Some students were told they were 'stupid' and ignored when they said they needed extra supports in the classroom. They ended up leaving school because they were lagging behind their peers and felt overwhelmed.[59] During our community engagements, one community member said that the children do not get support they need in the classroom, and end up getting 'kicked out of school'.[60] These children will often then have contact with the justice system.[61]

First Nations people who are deaf or hard of hearing, emphasised the need for greater supports at key transition points in their lives, especially through educational years.[62] A person's hearing impairment may be viewed as a behaviour of concern, which results in unnecessary interventions and delays in diagnosis and treatment. Teachers in the Torres Strait reported difficulties accessing formal supports because of the way in which the educational and disability supports are prescribed. One teacher expressed frustration over this, stating that she has to assume up to 50 per cent of her classroom can't hear her. She said that if the children's needs were properly identified, the school would be resourced to properly support them.[63]

Young people

We heard that First Nations adolescents with disability often have contact with the youth justice system.[64] In Public hearing 11, 'The experiences of people with cognitive disability in the criminal justice system', Ms Cheryl Axleby, a Narungga woman and CEO of the Aboriginal Legal Rights Movement in Australia, described how the young people she worked with came into contact with the criminal justice system:

> In my experience, some people with FASD skip or avoid school, interrupting their education, misuse alcohol and other drugs, be discriminated against because they are seen as 'aggressive', 'temperamental', or their slurred or unclear speech might be mistaken for drunkenness which makes them targets for over-policing.[65]

Professor Eileen Baldry AO described the compounding factors of disadvantage that draw people into the criminal justice system, but also enmesh them. She used the analogy of a 'spider web':

> It becomes stickier and stickier the more of these things that accumulate in your life. And eventually it is almost impossible to get out of that web. Because you do not have the leverages, you do not have the capacities, you don't have a community, you don't have the resilience, you don't have what other people who might have had supports throughout their lives do have.[66]

Witnesses described the long-term impacts of early contact with the criminal justice system, especially for First Nations children and young people with disability in out-of-home care.[67]

4.4. Settings of violence, abuse, neglect and exploitation

First Nations people with disability have told the Royal Commission about their experiences of violence, abuse, neglect and exploitation, including interpersonal, settings-based and structural violence.

We have heard about their experiences in various settings, such as schools, health care settings and disability services. First Nations people and organisations have identified key issues regarding access, quality and availability of services, particularly regarding the NDIS, as well as the barriers and expenses to obtaining disability diagnosis and support. Restrictive practices have been a key feature of their experiences in healthcare and school settings, as have incidences of physical violence and substandard care.

This chapter will also examine their experiences of domestic, family and sexual violence. We have been told about their vulnerability in some community settings, the lack of adequate access to shelters and housing, and the exposure of some groups, such as First Nations women, to family and sexual violence. First Nations people have also reported the extent to which they have acquired a disability such as a brain injury or psycho-social disability due to sustained violence.

Chapters 5 and 6 discuss what First Nations people have told us about their experiences in child protection systems and criminal justice settings.

Education

> I received, really, no education; I had to struggle every day, and I didn't want to go to school. I couldn't be bothered because it was so frustrating. I felt so angry and so I was called a 'troubled child'.[68]

First Nations students are over-represented in the cohort of students with disability. Thirty-six per cent of First Nations students had a disability in 2020, as defined by the Nationally Consistent Collection of Data on School Students with Disability (NCCD). This was double the proportion of non-Indigenous students with an NCCD defined disability (18 per cent).[69]

For many students with disability, exclusion from a safe and inclusive education in mainstream settings begins before kindergarten and continues until they leave school. From as early as attempts to enrol in primary school, messages from educational institutions are often that they do not belong and their support needs cannot be accommodated.[70] For First Nations students with disability, the barriers are even bigger.

The right to education is often described as a 'multiplier' right, as it enables access to other human rights.[71] Education is associated with better employment and health outcomes and control over a person's own life.[72] Completing and transitioning from school has been linked with greater social mobility and intergenerational outcomes.[73]

The school environment is a critical building block in the lives of First Nations children with disability.[74] Families shared their hopes for their children to thrive at school, both academically and socially. They feel a quality education and culturally appropriate schooling should underpin their child's development towards adulthood and potential employment.[75] High-quality, inclusive education is critical to help First Nations children avoid interaction with justice and child protection systems and enter into adulthood free from violence, abuse, neglect and exploitation.[76]

In many instances, however, First Nations families' aspirations for their children's school experiences were not realised. First Nations students with disability were bullied or subjected to restrictive practices, or could not access the resources to enable them to flourish.[77] We heard of a widespread lack of funding and support from the NDIS and education departments for them.[78] We also heard about them being excluded, suspended and expelled.[79] The effect of these negative experiences at school multiplies across the life course of First Nations people with disability.

We examined the experiences of people with disability, including First Nations people with disability, in the education system in:

- Public hearing 2, 'Inclusive education in Queensland – preliminary inquiry', which examined the implementation of policies and procedures relating to inclusive education of students with disability, with a focus on the Queensland government education system.
- 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'.
- Public hearing 24, 'The experience of children and young people with disability in different education settings'.

Volume 7, *Inclusive education, employment and housing* examines the Australian school system for students with disability, including the legislative framework and obligations under the Convention on the Rights of Persons with Disabilities (*CRPD*). It also sets out the Royal Commission's recommendations relating to the education system for students with disability, including First Nations students with disability. This chapter describes the educational experiences of First Nations people with disability.

The gap between the educational outcomes of First Nation students and their non-Indigenous peers in critical areas such as reading and numeracy persists.[80] This gap is worse for First Nations students with disability, who experience:

- a lack of cultural safety in the delivery of education programs and provision of supports and reasonable adjustments[81]
- exclusionary discipline[82]
- bullying and mistreatment by staff and other students[83]
- exclusion through low expectations[84]
- underdiagnosis and misdiagnosis of disability, which impacts on access to supports.[85]

Case study: The experiences of Quaden Bayles and Yarraka Bayles

Quaden Bayles is a First Nations child with disability who attends a public mainstream primary school in Queensland.[86] He was nine years old and in year 4 when he gave evidence at Public hearing 7 in September 2020.[87]

His mother Yarraka Bayles is a First Nations woman with connections to Wonnarua and Bundjalung people from New South Wales, and Birri Gubba and Gungalu from Queensland.

She also gave evidence at Public hearing 7 about Quaden's experiences at school.

Ms Bayles described the severe bullying Quaden endures from his peers. He is called names, pushed to the ground and left out. Because of this, Quaden sometimes does not want to attend school. The fallout on his mental health 'got to the point where sometimes he was attempting suicide multiple times a day'.[88] Ms Bayles said the response from the school was inadequate:

> The school hasn't done enough. My son's life is on the line. I'm keen to make changes. I'm sick of sounding like a broken record about not enough being done … They preach about anti-bullying, but nothing is in place … They haven't communicated to me about what they have in place or any policies they have.[89]

In a pre-recorded video, Quaden spoke about changes he would like to see to make school a better place for children with disability. His message to classmates who do not understand why their comments hurt him was: 'Just don't be rude to kids who have disabilities, and just be kind and be nice'.[90]

Ms Bayles stressed the importance of cultural safety in providing educational supports for First Nations students with disability.[91] A big issue for Quaden is feeling he is being treated as 'a kid with disability who is also a Murri kid'.[92]

Ms Bayles felt teachers lacked the knowledge to provide a culturally safe environment and appropriate supports for First Nations children with disability. She said:

> In my view, one of the problems is that cultural awareness training isn't compulsory within schools, it is up to schools to decide. It should be compulsory for all teachers. It's cross-cultural communication and helps people understand different approaches to teaching and learning, which is very beneficial.[93]

She noted the lack of diversity among students and staff. When Quaden was taught about Australian history, he was 'singled out' because he was one of the few First Nations children at the school. Once, Quaden told a teacher he referred to January 26 as 'Invasion Day' and partook in protest marches on Australia's national day. In response, the teacher provided him with a book about Captain Cook and told him to learn Australia's 'true history'.[94] This evidence reflects the findings of the Victorian Equal Opportunity and Human Rights Commission's 2012 report, *Held back: The experiences of students with disabilities in Victorian Schools*. It found a lack of cultural safety intensifies feelings of isolation for First Nations children with disability.[95]

Ms Bayles said Quaden, like many other First Nations children, had different needs than his peers. She said the lack of flexibility and 'one size fits all approach' to education programs was failing First Nations children.[96] For example, Quaden learns better when he is 'stimulated out in nature' and when teachers work with his strengths rather than from a 'deficit approach'.[97] She believes observing cultural protocols is even more important for First Nations children with disability.[98]

Ms Bayles explained that Quaden requires a support worker to assist him with toileting and supervise him in the playground.[99] The school initially provided him with a female support teacher, which Ms Bayles said was culturally inappropriate:

> he had told me that he didn't feel comfortable with her so he would just hold it all day. That meant that sometimes last year he had accidents and soiled his pants, which meant he got teased.[100]

Quaden told his mother his support teacher was also unkind to him and once told him he was 'the dumbest kid in the class'.[101] After speaking with the school, they arranged for a male First Nations support worker for him, and he was much more willing to attend school. 'He was happy, he was lasting all day, not even coming home early,' said Ms Bayles.[102] When the support worker is not there, however, Quaden gets anxious and will not go to school.[103] This causes significant disruptions for him.[104] Quaden said he would like another support worker, 'A Murri one, a real one. So when [redacted] is away, I can have that one and he's gonna be there'.[105]

Ms Bayles hopes to develop a First Nations education module 'to change the way schools are teaching our kids'.[106] Teachers and policy makers should take a holistic approach to education for First Nations students with disability. She believes this would benefit all children, whether or not they are First Nations or a student with disability.[107]

Bullying

Quaden's experience of bullying at school confirmed what we heard during engagements, private sessions, submissions and other public hearings.[108] The failure by schools to intervene to prevent bullying was also a common theme. First Nations children with disability described the effect bullying had on their social and emotional wellbeing, including suicidal ideation, avoiding school and dropping out.[109]

'Camilla' told us in a private session about the way students treated her daughter, 'Gracie'.[110] Camila said when Gracie was in year 5, she started to experience clandestine bullying, which was hidden from her teachers.[111] One morning, she woke up weeping at the prospect of going to school.[112] She asked her mum, 'Why am I so different? What's wrong with me?'.[113]

Participants in the Wangkiny Yirra 'Speaking up' research project research also described being bullied at school.[114] The bullying targeted their disability and their identity as First Nations children.[115] The bullying led to trauma and exclusion, and in some cases stopped them attending school out of fear for their physical safety.[116]

The project found that short absences due to bullying may lead to longer and even permanent absences from education.[117] As one participant said:

> I couldn't go [to school] actually. Nan stopped me because I had, yeah, I got in a fight there ... Yeah, against two girls, they just wouldn't stop, so I had no choice but to fight back. No, it wasn't safe at all, school. Yeah, so I just left and didn't go back.[118]

Exclusionary discipline and restrictive practices

We heard that First Nations children with disability are being prevented from participating in mainstream education through what is known as ‘exclusionary discipline’. Exclusionary discipline includes suspensions, detentions or expulsions. It can also include requests for parents to collect students early, and students attending school for shorter periods on the pretext of managing behaviours associated with their disability.[119]

Many community organisations we heard from were concerned about the expulsion of children with disability from schools. One organisation in Alice Springs told us that children with disabilities such as FASD, serious mental health issues and trauma from sexual abuse were being expelled for ‘acting out’ at school. At the same time, they were not getting support, despite repeated requests.[120]

During community engagements, we learned that expulsion was sometimes being used in places such as Fitzroy Crossing to exclude children with FASD from school for lengthy periods of time.[121] One community member said after children are expelled, they become increasingly enmeshed with the juvenile justice system: ‘they need more support but are getting less’.[122]

During a private session, the mother of one First Nations child with disability told us her son was put into a ‘padded cell’ for many hours adjacent to the classroom and regularly excluded from school activities.[123] She said he would come home with bruises on his body after being removed from the classroom.[124] In another private session, a parent said she requested a sensory learning environment for her six-year-old son to support his disability. She said instead the school locked him in a room with toys.[125]

The parent of a First Nations child, who is autistic and non-verbal, spoke about how teaching staff treated her son. She said he liked to shower at school as a self-soothing technique and his mother requested a male staff member to assist. She told us that after a number of months, teaching staff informed her they had been recording him showering to demonstrate his behaviour. She said the school dismissed her concerns about this.[126]

During Public hearing 7, we heard from Professor Linda Graham, Director of the Centre for Inclusive Education at the Queensland University of Technology. Professor Graham said students with disability, First Nations students and those in foster care are at greater risk of exclusionary discipline due to intersectional disadvantage.[127]

She highlighted the lack of publicly available data on suspensions and expulsions of students with disability.[128] Without such data, Professor Graham said, it is difficult to understand the scale of the problem and develop solutions. She noted ‘this absence is not because the data does not exist or that it is not collected’, but ‘because no school education provider in Australia publishes disaggregated suspension or exclusion data’.[129]

Data collected by the Royal Commission shows that First Nations students with disability are significantly more likely to be suspended than both First Nations students without disability and non-Indigenous students with disability.[130]

We were told that teachers do not always recognise students' behaviours as being associated with disability or trauma. Participants in the Wangkiny Yirra 'Speaking up' research project noted teachers could be inflexible with their teaching approaches, and about providing appropriate adjustments to manage these behaviours.[131] For some children with disability, the absence of appropriate adjustments can escalate 'behaviours of concern', which teachers mistake for wilful disobedience and responded to punitively.[132] We discuss 'behaviours of concern' in more detail in Volume 6, *Enabling autonomy and access.*

Teachers' lack of understanding of disability can affect students' learning and behaviour.[133] One participant in the Wangkiny Yirra 'Speaking up' research project said:

> I had this one [teacher] when I was only young basically tell me I was stupid because I couldn't write. That was really offensive. She made me feel like I was dumb, like she used to scream at kids. She – yeah, just no one really knew and no one really understood why I was like the way I was and I'd get in trouble shit times.[134]

The Victorian Aboriginal Child Care Agency raised concerns about this:

> The biggest issue is about the ability of staff and teachers to pick up behaviours that may be aligned with a disability or trauma instead of a behavioural issue. We know that for children who are presenting with autism and ADHD like behaviours there is little recognition for the impact of trauma and potential for a misdiagnosis is high. Mainstream schools are not equipped to support children with a disability and Aboriginal children showing trauma responses, and there is a lack of alternative schools that are better at supporting behavioural displays of disability but are more lacking in cultural safety.[135]

If teachers are not trained to identify disability and trauma, and provide appropriate supports, children are likely to fall behind, regardless of their learning ability. Another participant in the Wangkiny Yirra 'Speaking up' research project noted:

> So I'm very smart, very, very smart and I did all my ATAR classes, but it got so overwhelming. Especially with other things going on and because I was also diagnosed with depression and anxiety as well. So that didn't help and I got really overwhelmed and I dropped out of ATAR … but there's not really enough support in classes like that, especially ATAR, because they have to look after so many kids and then you kind of get left behind if you don't kind of sort it out.[136]

We also heard about the ongoing use of medication to control the behaviour of First Nations children with disability. Schools simply 'medicate them like that so they're no trouble', according to a First Nations community member in Tasmania.[137] The parent of an autistic First Nations child told us during a private session that the special education school refused to enrol her son unless she agreed for him to be medicated.[138]

Absence of appropriate disability supports

First Nations parents, caregivers and school professionals regularly identified a lack of disability-specific supports and resources as a major barrier to meeting the needs of students. Teachers and support staff highlighted the increasing pressure on them to be 'everything' to students and their families. An education provider in regional Queensland described the need for significant improvement in the way all agencies supported First Nations students with disability in the school environment. He told us:

> The multiagency [need] is a huge complexity because educators are educators. That piece we have to do together, we don't always get right.[139]

During a community engagement in the Torres Strait region, we were told executive staff had to provide one-on-one support to First Nations students with disability because of teacher shortages.[140] Educators expressed concern about whether some schools were meeting the individual needs of students with disability given the lack of targeted supports. The deputy principal at one school told us that the school did its best, but she never feels like they have done their job well enough.[141] She said that children in the Torres Strait do not get the same chance as children in Sydney, where she grew up.[142]

Similar issues were raised during engagements across the country. School staff expressed frustration over problems getting adequate funding because many First Nations children with disability were not formally diagnosed.[143] One school principal at an independent school told us they already faced considerable funding pressures as they were required to employ Aboriginal Language Officers and bus drivers. On top of this, they needed to find funding to adequately support their students with disability.[144]

During Public hearing 2, we heard of the challenges for families trying to access supports for their children through the Queensland Education Adjustment Program (EAP) 'verification process'.[145] The EAP allocates state funding to schools to support students with disability. Ms Loren Swancutt, Acting Regional Head of Special Education Services (Inclusion), North Queensland Region, told us that some families find the process difficult to navigate or lack the means to obtain a formal diagnosis.[146] She noted families sometimes choose not to have their child 'labelled' or do not identify their child as a having a disability.[147] The need to 'identify' or 'verify' a disability under the EAP does not necessarily reflect different cultural understandings of, and approaches to, disability.[148]

During an engagement in the Northern Territory, we were told the teacher-to-student ratio was often inadequate and this presented challenges for students and teachers.[149] We heard from one ACCO that schools in their community were finding the lack of classroom support frustrating as they teach a lot of children with a 'spectrum of behavioural disorders' linked to cognitive disabilities.[150] They said the structure is still one teacher to up to 28 children.[151]

Despite a formal policy of inclusive education, one school staff member told us children with disability in some parts of Queensland, including the Torres Strait Islands, simply 'don't go to high school'. This is because local schools are not able to cater for the needs of children with disability, meaning the only option is boarding school.[152]

Teaching staff also discussed the lack of accessible spaces at schools and long delays in providing necessary modifications to support First Nations students with disability. In one community, teachers told us that despite applying to their education department years earlier, they were still waiting on building modifications to provide students access:

> I did [a] first submission for the modifications when he was in year 5. The school had to adjust timetables, but he can’t access any of the classrooms or the library space. Teachers have had to get a trolley of books and bring them downstairs and that would be his access to the library.[153]

Exclusion through low expectations

We have heard that First Nations students with disability face low expectations from their peers and teachers.[154] They are denied opportunities to experience life and explore their potential because it is assumed their potential is limited.[155]

Cody Skinner, a Bidjara man who grew up in foster care, told the Royal Commission about his experiences in education and obtaining employment. Reflecting on his studies at TAFE, he noted the most challenging thing was other classmates judging his disability:

> I was the only person in my course with a disability. When I first started all my classmates would make fun of me and laugh, they said things like ‘oh he’s got a disability, I don’t think he’ll make it through’. I was determined to prove them wrong.[156]

A First Nations woman with disability told us it took her 10 years to complete an undergraduate degree, partly because of the university’s failure to provide reasonable adjustments.[157] She said, ‘[I] was told [I] should just be happy [I] passed rather than seek to achieve my best possible results’.[158]

First Nations Children who participated in the Wangkiny Yirra ‘Speaking up’ research project reported they were made to feel ‘dumb’, which eroded their self-confidence.[159] One participant said:

> That’s what affected me now probably with school … A bit hard if you kind of think ‘oh fuck, I’m too dumb, I can’t do it’.[160]

Participants also described how school could be positive experience when they were valued and included.[161] One student said:

> But then I got a really nice English teacher that year, he was amazing actually. I didn’t do too well in his class. I got really bad, but it still was really nice there, like he made it a bit more enjoyable.[162]

During our community engagements in the Northern Territory, we visited a number of schools for primary and secondary students that provide special/segregated education. The population of First Nations children with disability was relatively high in these schools, and included some students on child protection orders. One school told us that out of the 94 students enrolled, at least 70 per cent were First Nations children.[163]

Staff at these schools acknowledged the controversy surrounding special/segregated education. Nonetheless, they believed their schools were ‘doing good things’, even if there was a long way to go on inclusion.[164] They noted that mainstream schools in their area often dealt poorly with students with disability and steered students toward special/segregated schools.[165]

Staff and parents believed that special or segregated schools generally provided a learning environment better able to meet the needs of students with disability. This was primarily due to the specialised expertise of staff at these schools. Despite this, some parents and carers expressed frustration at the lack of disability training at these schools and said they had to repeatedly inform teachers about some types of disability, such as FASD.[166]

Staff at specialist schools said they were committed to ensuring First Nations students with disability had access to a quality education that would set them up for life. They emphasised an approach to learning that included developing life and social skills, as well academic outcomes. Schools pointed to the social enterprises run by their student bodies and highlighted instances where students had gone on to undertake apprenticeships and, later, successful employment.[167]

One principal emphasised the ‘preventative’ approach her school takes to support students through the use of behavioural support plans and access to onsite counsellors and occupational therapists.[168]

A Yamatji parent whose child attends a special/segregated school in Western Australia spoke about the changes in her child’s behaviour following what she described as an invasion of the child’s privacy and the use of restrictive practices. She told us he was non-verbal and the school took many months to let her know what had happened.[169]

Health

> … I was laid up in the bed and I was left there and they knew that I was a quadriplegic, but, then again, the nursing staff just presumed that I was just a drunk Aboriginal … And then I was laying there dehydrated and more patients were coming and they’re all getting treated first before I was getting any help.[170]

Throughout our inquiry we have heard that people with disability experience a number of barriers to accessing quality health care and treatment. A number of the Royal Commission’s public hearings focused on violence, abuse, neglect and exploitation of people with disability, including First Nations people with disability, when engaging with the health sector:

- Public hearing 4, ‘Health care and services for people with cognitive disability’, examined the barriers to health care for and systemic neglect by the Australian health system of people with cognitive disability, including those with intellectual disability, learning disability, dementia or acquired brain injuries, and some people with autism
- Public hearing 6, ‘Psychotropic medication, behaviour support and behaviours of concern’, examined the over-use and misuse of psychotropic medication for people with cognitive disability to address ‘behaviours of concern’
- Public hearing 10, ‘Education and training of health professionals in relation to people with cognitive disability’, examined how to strengthen the education and training of health professionals, including doctors, nurses, dentists, pharmacists, psychologists and speech pathologists, to improve health care for people with cognitive disability.

In Public hearing 5, ‘Experiences of people with disability during the ongoing COVID-19 Pandemic’, Commissioners observed that while the Australian Government recognised early on the increased risks First Nations people faced, it did not initially consider the specific needs of First Nations people with disability.[171] Commissioners recommended the terms of reference for the Aboriginal and Torres Strait Islander Advisory Group on COVID-19 should be amended to include providing advice with respect to First Nations people with disability,[172] and membership be extended to include at least one member to represent First Nations people with disability.[173] The Australian Government accepted and acted on these recommendations.[174]

Our health-focused recommendations in Volume 6*, Enabling autonomy and access* address the barriers to health care faced by people with disability. In this chapter, we consider the specific experiences of First Nations people with disability when engaging with the health system. We identify issues they encounter in health care that exacerbate health disparities. We highlight these issues for governments and others in the health system to consider and address when responding to our health-related recommendations in Volume 6. Resolving these issues in collaboration with First Nations people and their communities is critically important to realising the right to health for First Nations people with disability.

Poor health outcomes

In Public hearing 4, Dr Avery described his community-based research, which presented both participants’ testimony and statistical data collected by the Australian Bureau of Statistics. He concluded population data demonstrates that discrimination and social exclusion are experienced across First Nations communities, and cannot be dismissed as isolated examples.[175]

In 2018–19, only one in eight (12 per cent) of First Nations people aged 15 to 64 with a ‘profound or severe disability’ reported excellent or very good self-assessed health. This was around one-fifth of the rate reported by First Nations people with no disability (61 per cent).[176] First Nations people aged 15 to 64 with profound or severe disability were almost twice as likely to have faced barriers to accessing health services (65 per cent) as those with no disability (34 per cent).[177]

System-wide failings

During Public hearing 4, Dr Avery described a 'culture of avoidance' that begins at a health policy level and 'sets the tone for what Aboriginal and Torres Strait Islander people can expect to encounter in front line service delivery'.[178] Dr Avery described a number of 'system-wide failings' within the health system in Australia for First Nations people with disability. In particular, he highlighted a widespread refusal by policy makers to accept health inequalities for people with disability even exist:[179]

> [T]here have been active steps to dis-acknowledge the evidence of grave health inequalities experienced by Aboriginal and Torres Strait Islander people with disability, and a need for action is hidden behind this cloak of deniability [sic].[180]

Dr Avery expressed the view that one of the 'mechanisms of avoidance' within health policy, is where one part of the health system 'disgorges' responsibility on to another part of the system to address inequalities, which in some cases creates a 'circular reference of avoidance'.[181] He said:

> Aboriginal and Torres Strait Islander people with disability are in need of a sophisticated approach to address their health needs, in which all parts of a healthcare system come together collaboratively in accepting joint and several responsibility for attaining improvements in their health outcomes.[182]

Dr Avery suggested that addressing the complexity of the health issues affecting Aboriginal and Torres Strait Islander people with disability should be a collaborative exercise between the many parts of the healthcare system, and the disability community.[183] While this work has yet to be done, Dr Avery suggested the Royal Commission take steps to establish an initial platform for the structural reform that is required. His suggestions included instigating a systematic process that requires position holders at the various levels of the health system to account for what structures are, or are not, in place to safeguard against neglect and prejudice in the delivery of health care for people with disability.[184]

Our health-related recommendations in Volume 6, *Enabling autonomy and access* are targeted at different levels of the health system and, as we indicated earlier, should be implemented with the specific needs of First Nations people with disability in mind. Our broader recommendations in Volume 5, *Governing for inclusion* and Volume 11, *Independent oversight and complaint handling* are also intended to inform the type of structural reform in the health system that Dr Avery is suggesting

Case study: The experiences of Narelle Reynolds, Justin and Luke

Ms Narelle Reynolds is a Wiradjuri woman who has worked as an enrolled nurse and coordinated access to health services for First Nations families. Her sons, Justin and Luke, have an intellectual disability caused by a genetic condition called Fragile X Syndrome.[185] In Public hearing 4, Ms Reynolds described her challenges navigating the health system and advocating for her sons, despite being a health professional herself:

> well, they’re dismissive because I’m black, ‘What do you know?’ And because they’re the professional and they know better than me. And I find that really condescending.[186]

She felt she was not taken seriously by doctors when she had concerns about her sons as infants. This made it difficult to get an accurate diagnosis of their disabilities. The paediatrician initially told her Justin was autistic, nothing could be done for him and gave her the option of putting him in a group home.[187] The paediatrician did not suggest genetic testing or provide Ms Reynolds with any information about autism.[188] When Luke was born, she went back to the same paediatrician. She said, ‘I was basically told I was being an irate mother because … I couldn’t possibly have two autistic children’.[189]

In primary school, Ms Reynolds agreed to Justin being tested as part of Professor Gillian Turner’s research, and discovered that Justin had Fragile X. She underwent testing herself along with her other children and found Luke also has the condition.[190] She had never heard of Fragile X before and it was very difficult and emotional to raise the issue of testing with her broader family.[191]

Ms Reynolds said her sons have extreme fear and anxiety when going to hospital or other unfamiliar medical environments. Despite this, she struggles to get doctors and nurses to heed her advice on the adjustments her sons need to be able to access medical care and treatment safely.[192] This has made it particularly difficult for Luke to obtain a diagnosis and treatment for cancer.[193]

Challenges in providing cultural safety

As discussed earlier in this volume, we have heard that First Nations peoples’ access to health services is influenced by the cultural appropriateness of the services. As outlined in Chapter 2, cultural safety starts with services acknowledging that First Nations’ understanding of health and wellbeing is different to that of mainstream Australia. It encompasses social and emotional wellbeing, which connects the health of a person to the health of their family, kin, community, connection to Country, culture, spirituality and ancestry.[194]

It also requires health services to understand the intergenerational trauma and mistrust of institutions that are the legacy of colonisation and the experiences of the Stolen Generations. In Public hearing 8, ‘The experiences of First Nations people with disability and their families in contact with child protection systems’, Commissioner Oscar AO described the ‘real and justifiable concern’ of some First Nations women who ‘fear having children removed for no reason’.[195] She went on to say:

> Having no choice but to access services that repeatedly pursue punitive action against families for having a child with complex health needs can cause extreme anxiety. It is for this reason that some Aboriginal and Torres Strait Islander people regard health care services, such as hospitals, as a last resort.[196]

Dr Tracy Westerman AM is a Njamal woman of the Pilbara region who holds a PhD in clinical psychology. She said it is a significant challenge for practitioners who engage with First Nations people to apply culturally competent service delivery.[197] For Ms Reynolds, many health services do not know how to provide services to First Nations people with disability.[198]

The Lowitja Institute's response to our *Issues paper on health care for people with cognitive disability* acknowledged that the mainstream health system is moving towards cultural safety through regulations around health practitioners and health services. However, the institute said this must be coupled with broader service reforms, such as ensuring provision of services on-Country, facilitating traditional medicines and healing practices within mainstream services, and building community-controlled health and wellbeing services.[199]

In Public hearing 30, 'Guardianship, substituted and supported decision-making', 'Anthony' described his concerns about finding his mother 'Killara' in 'an apparent catatonic-like state' with serious untreated medical conditions when she was living under a public guardianship order in a locked mental health facility.[200] Killara is a member of the Stolen Generations and has a cognitive impairment and epilepsy.[201] Anthony told us how Killara's health improved when he became her guardian and was able to link her into a culturally appropriate Aboriginal medical service:[202]

> It was important to me to have my mother's health reviewed by a culturally appropriate health service. A culturally appropriate health service in my view is one that is able to tailor their service to the cultural needs of the Aboriginal community, and understands the many barriers that exist for Aboriginal people accessing health. It's about cultural safety and knowing that you are not going to be looked at in the wrong way. It is also about having a family approach and facilitating referrals to Aboriginal Allied Health Services. I believe that having an Aboriginal health service has been extremely beneficial for my mother.[203]

As discussed in Chapters 7 and 8, sustainable long-term funding is needed to increase the availability of First Nations–specific services, including in ACCHOs. However, during a private session, one woman pointed out that even Aboriginal Medical Services are not necessarily culturally safe.[204] She said staff are often not First Nations people and do not always have a good understanding of First Nations culture.[205] In general, she found staff at Aboriginal Medical Services lacked a good understanding of disability.[206]

Volume 6, *Enabling autonomy and access* provides further information on the experiences of First Nations people with disability and guardianship.

Lack of adequate assessment and diagnosis of disability

In a number of public hearings, we heard about the high prevalence of undiagnosed disability among First Nations people, particularly of FASD and other forms of cognitive impairment, psychosocial disability and hearing impairment. In Public hearing 16, 'First Nations children with disability in out-of-home care', we heard 'there is a chronic problem of under-identification and under-diagnosis of disability of Aboriginal and Torres Strait Islander children in OOHC [out-of-home care]'.[207]

In Public hearing 8, Commissioner Oscar AO told us about her involvement in ground-breaking First Nations community-led research that confirmed a high prevalence of FASD in the Fitzroy Valley region of the Kimberley, which prior to the research had been undiagnosed and to a large degree hidden.[208] Commissioner Oscar AO said the research 'provided a snapshot in time that has given us an indication that there is likely to be a large prevalence of undiagnosed cognitive and physical disabilities across the region'.[209] She also said that the almost universal experience of early-life trauma was a significant finding.[210]

Commissioner Oscar AO talked about a follow-up study looking at the same cohort of children, at around 17 to 18 years of age, to identify adolescent needs and protective and risk factors for adversity in adolescents. She said:

> Sadly, I'm advised that those children who are now part of the Bigiswun project have received little to no support in their response to their identified diagnosed needs. As young adults, these children are said to be experiencing extreme mental health issues leading to suicidal ideation, and that's a huge and enormous pressure for this community.[211]

In a number of hearings, we examined the negative consequences a lack of appropriate assessment, diagnosis and treatment can have on life pathways. This includes low educational attainment, difficulties in sustaining tenancies, and increased risk of involvement in the child protection and justice systems.

In Public hearing 11, Ms Cheryl Axleby, a Narungga woman with family ties across South Australia and CEO of the Aboriginal Legal Rights Movement in Australia said that entry into prison is often the first place a person is assessed and diagnosed with a disability.[212] She said this reflects a failure to provide earlier opportunities in the health and education systems to identify disability and put in place supports that may have reduced the risk of the person coming in contact with the criminal justice system.[213]

Some of the factors that contribute to First Nations people not being able to obtain a disability diagnosis were explained by witnesses in Public hearing 4. As indicated in Chapter 2, Dr Avery said these factors include cultural differences about the conceptualisation of disability in First Nations communities. He gave, by way of example, the challenges of diagnosing FASD in remote regions, which include:

- people just do not see the disability because it is a more inclusive culture
- the need to consult a range of health professionals to get a diagnosis, for example, a paediatrician, a child psychologist
- stigma, blame of the mother and concern about how the child might get labelled by a diagnosis, which mean people avoid engaging with the system.[214]

During Public hearing 16, Ms Catherine Liddle, CEO of the Secretariat of National Aboriginal and Islander Child Care, outlined a number of barriers to assessment and diagnosis of First Nations children. These include limited access to paediatricians in remote areas, culturally unsafe practices, lengthy wait times and high costs.[215]

Research has shown that there is a risk of error in applying mainstream psychological tests and assessments to First Nations clients.[216] Dr Westerman spoke in Public hearing 8 about a number of factors linked with cultural bias that can affect the reliability of assessment results for First Nations people.[217] These occur in the way tests have been constructed and in practitioner bias. They can also stem from a lack of cultural knowledge in applying and interpreting the results.[218]

According to Dr Westerman, researchers continue to use testing tools and assessment measures for First Nations people that inadequately account for the cultural differences of First Nations people.[219] Inappropriate testing and assessment leads to misdiagnosis, or a failure of diagnosis.[220] She felt that psychological and psychiatric diagnosis should follow a holistic assessment process in which the application of an appropriate psychometric test is one part.[221]

This evidence was supported by Ms Liddle during Public hearing 16. Ms Liddle said culturally appropriate First Nations assessments were ‘virtually non-existent’.[222] She said that assessment frameworks based on Western methodologies do not have the right cultural frameworks to assess the disability support needs of Aboriginal and Torres Strait Islander children within a holistic framework.[223] For example, social and emotional wellbeing assessment tools often ignore important aspects of First Nations children’s social and emotional wellbeing, such as spirituality and cultural connection.[224]

Ms Liddle said her organisation was also concerned that many mainstream practitioners undertaking these assessments do not employ a trauma-informed approach, which affects the results.[225] Assessments are often completed in a ‘sterile clinical setting’, which ‘discourages open conversations and engagement and is culturally unsafe’.[226] Better outcomes can be achieved when time is taken to build trust with the child, and holistic approaches ‘integrate additional steps in the process such as counselling’.[227]

Case study: The experiences of ABK

In Public hearing 6, we heard about ABK, a First Nations young person living in northern Queensland who has autism and a ‘severe intellectual disability’. He is predominantly non-verbal.[228] His advocate, Ms Mullins told us that as ABK lived remotely, he did not have any early intensive engagement with occupational therapy, psychology or speech services. Ms Mullins said this lack of early intervention had a cascading effect, causing problems in all other parts of his life.[229]

When Ms Mullins first met ABK, he was ‘living like he was a caged animal’, locked in a room with a mattress on the floor and some bottle caps to play with.[230] ABK had been prescribed various psychotropic drugs, including a stimulant and antipsychotics from the age of five.[231] Ms Mullins said she was concerned about the potential for ABK to experience adverse effects from taking the antipsychotic risperidone.

Ms Mullins detailed the considerable difficulties ABK, his family and she, as his advocate, have had in obtaining appropriate disability and behavioural supports to assist him. He also experiences difficulties in accessing appropriate, consistent medical care from health practitioners on an ongoing basis.[232]

Ms Mullins described how the actions or inactions of disability service organisations, a behaviour support practitioner, and medical practitioners affected ABK and his behaviours.[233] She contrasted this with his much more positive situation at the time of the public hearing, with a new highly trained, expert and responsive care and support team.[234] She stressed the problem of accessing experienced and qualified therapists and supports in regional Queensland.[235]

Diagnostic overshadowing

As discussed in Volume 6, *Enabling autonomy and access*, 'diagnostic overshadowing' is a particular risk to the provision of safe and quality health care for people with disability. Diagnostic overshadowing occurs where health practitioners attribute symptoms or behaviours to a person's disability rather than seeing them as indicators of particular health problems or conditions unrelated to the disability. In Public hearing 4, Dr Avery told us that diagnostic overshadowing compromises the quality of health care even more when it intersects with institutional racism.[236]

During Public hearing 28, 'Violence against and abuse of people with disability in public places', Ms Tracy Barrell OAM, a former Paralympian gold medallist, described that she is often 'ignored' when she tries to communicate her health needs and concerns to doctors.[237] A series of medical interventions, in which medical professionals did not take her concerns seriously, led to a significant reduction in the function of her arm.[238] Ms Barrell told us that a canula to treat a spinal cord infection was left in her arm for too long, and caused a blood clot.[239] She insisted to the nurses and doctors that something was wrong, but was not treated for the clot for a number of days.[240] Due to these delays, she was required to undergo surgery on her elbow and lost significant function in her arm. She had previously used a skateboard for mobility and did not require carers, but subsequently required a wheelchair for mobility, and full-time carers.[241] Ms Barrell said:

> I have often felt that doctors and nurses don't listen to me, even though I understand my disability and my body. They are so focussed on my disability, I am often ignored when I try to communicate to them about my health issues.[242]

In a private session, a man described an experience in hospital where he felt his disability was not appropriately considered. He said nurses administered incorrect medication and told him his body cramps were 'behavioural'.[243]

In another private session, a woman told us that when her mother entered a nursing home, staff did not believe the pain she was in and the supports she needed.[244] Her mother had a fall in her bathroom because the home did not provide the equipment she needed. When she complained of leg pain, she was not taken seriously, and it was several weeks before an x-ray revealed her legs were fractured and she required hospitalisation.[245]

Family and domestic violence

First Nations people with disability are disproportionately affected by family violence, and also face greater barriers to support, services and justice. Research shows that First Nations women are particularly subjected to intimate partner violence, and are more likely to experience physical violence than First Nations men with disability or non-Indigenous women with disability.[246]

The Royal Commission has heard evidence on First Nations people's experiences of family violence at hearings, as well as commissioning research on this issue.[247] First Nations witnesses gave evidence at Public hearing 17, 'The experience of women and girls with disability with a particular focus on family, domestic and sexual violence'. This hearing also had a closed session of LGBTIQA+ people with disability, including First Nations participants. Witnesses shared their experiences of family violence through their lives, as well as the impacts of the intergenerational trauma on them.

First Nations women with disability also gave evidence relating to experiences of violence, at Public hearing 8, 'The experiences of First Nations people with disability and their families in contact with child protection systems'. Their evidence emphasised the connection between family violence and child removal. They also described experiences of racism and ableism when they needed help.

The term 'family violence' is preferred by First Nations communities as it better reflects the relationships in which violence can occur, including extended kinship networks.[248] As such, 'family violence' or 'family and domestic violence' are the terms used in this chapter.

The context of family violence for First Nations people with disability

The legacy of colonisation and dispossession described earlier inform experiences of family and domestic violence among First Nations people. Participants in the Wangkiny Yirra 'Speaking up' research project considered family violence a consequence of colonisation.[249] This context means the experiences and causes of family violence against First Nations women are distinct from the experiences of non-First Nations women.

In a study on preventing family violence in Aboriginal and Torres Strait Islander communities, participants rejected official narratives on the causes of violence against women and other family members, which focused on 'male power, gender inequality and dominance'.[250] Instead:

> Aboriginal women and men in this study discussed multiple crises in their communities, among which the powerlessness of Aboriginal men since colonisation remains a prominent thread.[251]

Participants in the Wangkiny Yirra 'Speaking up' research project similarly raised concerns that policy responses placed too much focus on gender 'to the detriment of other relevant issues'.[252] Participants noted First Nations perpetrators of violence have their own histories and experiences of violence, trauma and abuse.[253] One woman said:

> There's no men's outreach for him, there's nothing for him. Nobody goes to him. [He] is totally deaf … [from physical abuse in early childhood], and he hasn't done nothing about it … he was sexually abused as a child ... counselling comes in every two weeks … [drugs] helps him cope, I see it. [254]

Participants in the Wangkiny Yirra 'Speaking up' research project reported 'extreme, prolonged violence from multiple intimate partners throughout their lives'.[255] The research findings indicate that First Nations women with disability experience 'substantially heightened barriers to leaving a situation of [family and domestic violence]'.[256] The report also recognises that family and domestic violence is itself 'a cause or contributor to disability', and while there are usually many factors behind the development of disability, many women who participated in the study drew direct links between the violence they had experienced and their disability.[257] Grief, loss and child removal were reported as causes of trauma and psychosocial disability.[258]

At Public hearing 17, Ms Thelma Schwartz, Principal Legal Officer, Queensland Indigenous Family Violence Legal Service, spoke about how First Nations women and girls with disability experience 'a complete lack of respect … recognition of who they are …recognition of their inherent worth and what they bring to society'.[259] Ms Schwartz said First Nations women are invisible in Australian society, and that this invisibility is 'particularly amplified' for women and girls with disability.[260] She said: 'We are not seen. We are ignored. We're an add-on, we are a tick and flick.'[261]

Ms Schwartz described First Nations women and girls' experience of systemic pressures, including abuse, as being 'compressed and compacted'.[262] Ms Schwartz said:

> I'm tired, and I get this from my clients, you know, we want a service but there is nothing because people don't see us. And it's even amplified if there is disability. I find that really heartbreaking, especially when I'm out bush and you are dealing with clients on the ground where it is so hard generally to have regular service and good service and people who are adequately trained to address people's issues and concerns. But then you go through that additional lens of being Aboriginal or Torres Strait Islander and then you add on the disability feature. It just amplifies it for me.[263]

Ms Schwartz said this invisibility is driven by perceptions and stereotypes around race.[264] She also spoke about the misconception that violence against First Nations women is 'an Aboriginal and Torres Strait Islander problem'.[265] Rather, the perpetrators of family and domestic violence against First Nations women and girls in Australia are men and women of all cultural backgrounds. Ms Schwartz said the issue needs to be seen as an Australian problem, rather than through a lens of a First Nations people's problem.[266]

Four case studies: Experiences of Etana, Kobie Hicks, Belle Stevens and Shontaya

First Nations women with disability shared their experiences of family and domestic violence at Public hearings 17 and 8. Below we have outlined the stories of 'Etana',[267] Kobie Hicks, Anabelle ('Belle') Stevens, and 'Shontaya'.[268]

Etana is a First Nations woman from Northern Australia who has experienced periods of psychosocial disability.[269] She told us she has experienced violence from her family and her long-term partner.[270]

Etana framed her experience of family violence through her understanding of the intergenerational trauma suffered by her family and ex-partner. She explained:

> I do not blame, nor hold resentments towards, those people in my life who have been violent or abusive towards me or who I have witnessed be violent towards one another. Each of the people in my life who have been violent or abusive to me and each other were themselves victims of violence and abuse in their own childhoods and adult lives.[271]

This began with Etana's grandparents being removed as part of the Stolen Generations. She said her grandparents:

> never got to see their parents, families, homes or speak their own language again until they were adults themselves and went searching for where they came from. Because of these experiences [they] were unable to understand love or how to raise my family in loving or nurturing way. This is because they were never shown or understood love themselves.[272]

Etana's mother experienced racism and abuse from her father, and has been mentally ill for most of her life. She abused Etana as a child and into adulthood. Etana explained she now understands the connection to intergenerational trauma:

> through trauma she carries in her DNA and from her own experiences of violence and the lack of support network around her. Because of this trauma she basically did not know or understand how to be a mother, she was not blessed with the positive genetics and opportunities to turn things around and break the cycle of trauma and violence.[273]

Etana told us her childhood experiences of violence affected her adult relationships.[274] As she never knew her father, she wanted her children to know theirs. Consequently, she found it very difficult to leave their father despite his violence toward her.[275]

Kobie Hicks is a Gubbi Gubbi woman with intellectual disability, depression and personal stress disorder.[276] She described her experience of abuse in multiple foster care settings.[277] She said she was not believed by child safety services when she disclosed abuse.[278] Kobie's experiences highlight problems of abuse of First Nations children in out of home care in Australia, which is explored further in Chapter 5 of this volume.

Later in life, Kobie described another instance of not being believed, this time by police. She recalled her partner had slammed her head against concrete, but when police attended and she tried to explain what happened, they identified Ms Hicks, not her partner, as the perpetrator of the violence.[279] Ms Hicks reflected on how her experiences impacted her relationships as an adult, leading her to normalise domestic violence. Support from WWILD, an organisation supporting people with intellectual disability who have experienced violence, has helped her understand what is and isn't safe in relationships:

> I always thought [domestic violence] was the answer, like, until I learned about the domestic violence circle through WWILD. I didn't understand, like, what was safety, what wasn't safe.[280]

Belle Stevens experienced family violence and institutional abuse in childhood, as well as violence and abuse as an adult. Belle is a First Nations non-binary person living with intellectual disability. Belle described experiencing '50-plus years of … nothing but mental, sexual and physical abuse' and feeling like they were 'put on this earth to be abused'.[281] Belle's experience illustrates how, for First Nations people with disability, violence can continue or be repeated across the life course. Belle's evidence also illustrates the life-long impacts of intergenerational family trauma and dislocation.

Belle was abused from the age of four and believes their mother knew but did not protect them.[282] Although they sought help on a number of occasions, this did not change their situation. As a result of these experiences, Belle finds it very difficult to trust people, services and organisations.[283]

First Nations women with disability also experience child protection involvement due to family and intimate partner violence and abuse.[284] In Public hearing 8, Shontaya, a proud First Nations woman, described her close-knit relationship with her family, and her overwhelming love for her three children. She also told the Royal Commission about the severe and prolonged violence she was subject to by her former partner, which began in pregnancy.[285] Shontaya was severely injured and hospitalised as a result of his violence.[286]

This violence was the context for child protection involvement and subsequent removal of Shontaya's children.[287] While she was physically injured and recovering, the South Australian Department for Child Protection assessed her as having 'low intellectual functioning', and sought long-term guardianship over her children. She told us that despite all her efforts to leave her violent partner, hold him to account through the justice system, and get support, she felt that the assessment of low intellectual functioning changed everything.[288]

First Nations witnesses who gave evidence about their experiences with the criminal justice systems were also subjected to family and sexual violence.[289] This is discussed in Chapter 6 of this volume.

The experiences of young people

Many of the children who participated in the Wangkiny Yirra 'Speaking up' research project reported witnessing violence and experiencing anger in response to grief and trauma.[290] For some children, their disability contributed to difficulties regulating and controlling their emotions. Children said this anger would at times be directed toward family members, and could lead to getting into trouble with police, and being suspended from school or excluded from community facilities.[291] One participant said:

> I mean it affected mum a lot. She got the brunt of everything, because I would be really angry and I would take it out on her. So, it was more people that were closer to me.[292]

Children also described the impacts that family and domestic violence had on them, including:

- difficulties sleeping[293]
- difficulties with concentrating and sensory processing at school, affecting attendance and performance[294]
- bullying by peers directed at the child's identity as First Nations or a person with disability, affecting social and emotional wellbeing and self-esteem[295]
- ineffective interventions by teachers, and punishment for retaliation against bullying[296]
- a strong sense of guilt or shame.[297]

Young First Nations people with disability are over-represented in the out-of-home care and juvenile justice systems.[298] The evidence presented to the Royal Commission, and the findings of the Wangkiny Yirra 'Speaking up' research project indicate family, domestic and sexual violence is often a factor in their experiences. This is discussed further in Chapters 5 and 6 of this volume.

Barriers to reporting and seeking support

> Being in a domestic violence relationship completely destroys and breaks a person, there is nothing in here to build us back up and help us find our strength and voice again.[299]

Public hearing evidence and research identified that First Nations people with disability experience additional barriers when reporting family violence or seeking support.

An issue raised in evidence and research was that First Nations women were not believed, or not supported, when they disclosed family and domestic violence to police. While some women reported supportive responses from police,[300] others were disbelieved or misidentified as an aggressor, as described by Ms Hicks,[301] and by participants in the Wangkiny Yirra 'Speaking up' research project.[302] This was identified as a particular risk for First Nations women with disability by expert witness Ms Schwartz.[303] This may contribute to First Nations people's broader mistrust of police and other government services, even when they need support.[304]

Research also identified that a 'well-founded fear of repercussions from child protection, and related issues around loss of home and community' is a significant barrier to reporting incidents of family and domestic violence.[305] Further, participants in the Wangkiny Yirra 'Speaking up' research project noted that incarceration as a response to violence did not rehabilitate First Nations men.[306]

Cultural safety was described as a critical issue for First Nations women when seeking support.[307] They also described breaches of privacy and under-resourcing of family violence services as barriers.[308] The women who participated in the Wangkiny Yirra 'Speaking up' research project also emphasised the importance of culturally safe therapeutic interventions for First Nations men to help them heal from their trauma to help break the cycle of abuse.[309] The Wangkiny Yirra 'Speaking up' research project identified the need for 'greater intersectoral collaboration between systems and a stronger understanding of how trauma and family violence feed into the many interrelated issues women may have'. The report notes that domestic violence services should be resourced and well equipped to work with women with disability, given the high rates of violence against them.[310] It found that cultural safety and trust were the 'most important factors impacting women's willingness to access a service related to their health and disability'.[311] The report also connected the gaps in data on the family violence experiences of First Nations people with disability with gaps in service delivery, noting that sufficiently robust data is required to inform targeted, data-driven policy responses, funding allocation and service delivery.[312]

Endnotes

1 Exhibit 8-24, 'Statement of Richard Weston', 23 November 2020, at [40]; Transcript, Richard Weston, Public hearing 8, 27 November 2020, P-425 [3–24]; Exhibit 8.21, 'Statement of Candice Butler', 16 November 2020, at [18–19]; Exhibit 8-22, 'Statement of Dana Clarke', 19 November 2020, at [26]; Exhibit 8-7, 'Statement of Professor Daryl Higgins', 12 November 2020, at [31], [35]; Exhibit 8.6, 'Statement of Thelma Schwartz', 20 November 2020, at [39]; Exhibit 8.3, 'Statement of June Oscar AO', 17 November 2020, at [18]; Exhibit 8-26, 'Statement of Professor Clare Tilbury', 20 November 2020, at [30]; Human Rights and Equal Opportunity Commission, *Bringing them home, Report of the National Inquiry into the Separation of Aboriginal and Torres Strait Islander Children from their Families*, Commonwealth of Australia, 1997, p 197; Australian Law Reform Commission, *Pathways to Justice–Inquiry into the incarceration rate of Aboriginal and Torres Strait Islander peoples*, Final report, Report no 133, 2017, p 41; Megan Davis, *Family is culture: Independent review into Aboriginal and Torres Strait Islander children and young people in out-of-home care in New South Wales*, Final report, October 2019, pp 21–23.

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5. Child protection

Key points

- First Nations parents and children with disability are over-represented in child protection systems.
- First Nations children and parents with disability are a distinct population group requiring specific care, support and resources.
- First Nations people with disability and communities should participate in all decision-making on programs and policies that affect them.
- First Nations children enter or are in out-of-home care with undiagnosed disability, and they often remain undiagnosed while there.
- A lack of cultural safety, and bias in assessment and diagnostic tools can lead to inaccurate assessments and diagnostic errors.
- A lack of early support for First Nations parents and children with disability can contribute to increased contact with child protection systems, particularly in remote areas of Australia.

5.1. Introduction

We considered the experiences of First Nations people with disability and their families in contact with child protection systems, including out-of-home care, in the context of the ongoing gross over-representation of First Nations families in these systems across Australia.[1] This is well established and has been the subject of a number of past inquiries.

What has not been the focus of past inquiries is the extent to which First Nations parents and children with disability are over-represented in child protection systems. We examined this issue, and the practices and decision-making processes of those systems in two public hearings:

- Public hearing 8, ‘The experiences of First Nations people with disability and their families in contact with child protection systems’, focused on the child protection system up until a child, or children, enter out-of-home care.
- Public hearing 16, ‘First Nations children with disability in out-of-home care’, focused on First Nations children with disability in out-of-home care.

Witnesses at these hearings described the effect of child removal on their lives. They shared the cycle of intergenerational trauma and the devastating effects on connections with family, culture and Country. First Nations people with disability drew links between child removal and later contact with the criminal justice system, experiences of family and domestic violence, and poor education and health outcomes. We were told of issues with disability screening and assessment processes, including a lack of cultural competence in these processes. People expressed concern that disability is considered a risk factor for child removal. The issues identified in public hearings 8 and 16 emerged as themes across our work.

People also told us about their experiences of violence, abuse, neglect and exploitation in connection with child protection systems in private sessions and submissions, and at community engagements.

We recognise the important role that state and territory statutory child protection authorities and child safety staff play in ensuring the safety of children and young people. We understand there will always be circumstances where a child must be removed from their family in order to prioritise the child's safety. We recognise the difficulty faced by child safety staff in making these decisions.

The purpose of this chapter is to highlight the intersection of disability and child protection with a focus on what First Nations people told us.

5.2. What gets counted matters

> If you cannot understand the numbers of children and young people who require a service, or the number of Aboriginal and Torres Strait Islander parents with a disability who are having their children removed, then you cannot design an appropriate service system to assist them.[2]

We learnt in Public hearing 8 that not all state and territory child protection authorities routinely collect or analyse data on the disability status of parents in contact with child protection systems.[3] In Public hearing 16, we learnt it is likely First Nations children with disability are over-represented in out-of-home care.

National data from 2019–20 shows that 6 per cent of Australian children are First Nations but they account for 41 per cent of children in out-of-home care.[4] While there is data about First Nations children in out-of-home care, the number and proportion of them in out-of-home care who also have a disability remains unclear. The number of parents with disability in contact with child safety services is also not known.

Most states and territories reported that where information on the disability of parents and families is collected, it was of insufficient quality to enable the extraction or reporting of reliable datasets.[5] There is a large proportion of children in out-of-home care with ‘unknown disability’ status.

Although most states and territories reported they capture data on the First Nations status of parents,[6] New South Wales, the Northern Territory and South Australia are the only jurisdictions that have made it mandatory.[7] Queensland and New South Wales indicated they collected information about parental disability status but acknowledged the information is not consistently collected or is only collected on a ‘case by case basis’.[8]

New South Wales has commenced projects to design, collect and interpret data relevant to First Nations people with disability.[9] In South Australia, the disability status of a parent and child is routinely collected by the Department of Human Services on referral but the department acknowledged that data collection on disability status, and data linkage requires improvement.[10]

States and territories noted that where this data is collected, it may be used to inform case management and risk assessments of children and young people, and to inform the delivery of reasonable adjustments or other supports.[11]

Mr Richard Weston, a Meriam man and former CEO of the Secretariat of National Aboriginal and Islander Child Care (SNAICC), explained that the absence of reliable data affects the ability of states and territories to design and implement effective evidence-based policy.[12] The Australian Government accepted there ‘are a number of gaps in and limitation of National-Level data’, which ‘limits its usefulness’.[13]

Ms Dana Clarke, a Worimi Biripi woman and Chairperson of AbSec – NSW Child, Family and Community Peak Aboriginal Corporation, explained that without access to data about First Nations children and parents with disability in out-of-home care and in contact with child protection systems, ACCOs and other services are unable to develop appropriate services to meet the needs of First Nations families.[14]

In submissions following Public hearings 8 and 16, Counsel Assisting considered at length the issue of data about First Nations families in contact with child protection systems.[15] Although there is a lack of accurate, disaggregated population-level data, we accept Counsel Assisting’s submissions that First Nations parents and children with disability are likely to be over-represented in child protections systems.[16]

Our recommendations directed to a nationally consistent approach to data collection on disability status are set out in Volume 12, *Beyond the Royal Commission.*

5.3. What we were told

I would like to know that people with disability won't go through the same pain, torment and flashbacks that I have been through.[17]

We were advised that to properly understand the experiences of First Nations people with disability in contact with child protection systems, including out-of-home care, the legacy of historical policies and the intergenerational experience of trauma must be acknowledged and understood.[18] We address the ongoing effects of colonisation, dispossession and the Stolen Generations in Chapters 1 and 2. Many people who told us of their experiences with child protection and out-of-home care raised these issues with us. In this section, we outline other themes that emerged through what we were told at hearings and in private sessions, submissions and community engagements.

Where we set out what people have shared with us in private sessions, submissions and at community engagements, we have done so to reflect the voices of First Nations people with disability. The views expressed are those of the person, not findings of the Royal Commission.

First Nations children with disability

Many of the First Nations people with disability and organisations who provided evidence or made submissions described violence, abuse and neglect experienced in out-of-home care.[19]

Justen Thomas, who lives with epilepsy and intellectual disability, told us of his removal into a children's home after being 'molested by a man' outside his family when he was 11 or 12 years old.[20] He described removal to the children's home as 'triggering' of his trauma:

> I didn't recognise my own trauma, I realised that I had – never saw me as behaviour problems, I was never – I had any kind of help, but I had to fend for myself as a child.[21]

Mr Thomas said he started to have seizures at around the time of his removal from his family.[22]

'Melanie',[23] whose experiences we outline in Chapter 6, was taken into care at the age of four, after probable sexual abuse.[24] Melanie lived in foster care as well as residential institutions.[25] Melanie explained:

> Things didn't go right there with sexual abuse, then I got transferred to, to institutions … They were terrible horrible and brutal they were no place for children. I had to fight to stay alive. I stayed strong even though I was sexually, physically and psychologically abused.[26]

A young person with disability identified as ‘IL’ said he had been in care since he was four or five years old, and in and out of jail since he was 10.[27] He said he had many foster care placements and experienced multiple instances of physical and other abuse.[28] IL described an incident when he was about eight years old, saying:

> I was sitting on the couch, watching TV, eating my breakfast. The carer – the foster carer walked up to me, kicked me in the jaw and I spilt the plate, and then he got angry and then started hitting me more because I made a mess in the loungeroom. And then I went to school, and then I had a bad day and then they was going to suspend me. I was crying at, like, when I was little, you know, I was crying in the office telling them, ‘No. No, I don’t wanna go back home. I don’t wanna go. They might bash me.’[29]

‘Miriam’ is a Warlpiri youth with disability.[30] Her former foster carer, ‘Grace’,[31] told us about Miriam’s experiences of being bullied and abused by older children when she was aged seven and living in a residential care facility.[32] When Miriam was 10, Grace discovered she had developed a substance abuse problem, sniffing glue, nail polish remover and permanent markers. She also suspected Miriam was inhaling aerosols, which she described as ‘chroming’. Grace stated Miriam admitted she had learnt ‘the substance abuse behaviours’ at the residential care facility.[33]

During a private session, a young First Nations man told us he was sexually, physically and emotionally abused by his foster family, and medicated to the point of collapse.[34]

We received a submission from a First Nations man with disability who told us about being removed from his mother at age seven after she was hospitalised. He described being beaten and abused by the whole family, which included a man, woman and their three adult children. He said when he found out his mother had returned from hospital, he kept running home. He said the family put a dog collar on him, tied him to a tree and made sure their vicious German shepherd watched him all night.[35]

An elderly First Nations man with disability described in a private session the impact his removal from his mother and his abuse throughout his childhood had on his ability to be a good husband and father.[36]

A First Nations woman with disability provided a submission in which she explained she and her sister were placed into a group home when she was 11 years old.[37] She described being physically and sexually assaulted by a carer.[38]

In response to our *Group homes* issues paper, an advocate told us about a First Nations man in his 30s who was removed from his family as a young child. He was placed in a children’s respite facility where he was sexually abused and kept in a cage:

> This Aboriginal family did nothing wrong but be Aboriginal. They had their own ways which was deemed by the state to be not good enough. But all the state provided was neglect and trauma.[39]

We heard about the ongoing effects abuse in care has had on First Nations people with disability, including lifelong trauma. Some link the trauma from these experiences, and the lack of response from systems meant to protect them, to their psychosocial disability.[40] A man told the Royal Commission he was a victim of physical, sexual and 'mental' abuse while in out-of-home care. He described later serving prison sentences in two jails, and having long periods of confinement. He told us he has severe depression, post-traumatic stress disorder and suicidal ideation because of his experiences in the home and jail.[41] He said, 'the demons from this still live in my world, with this I find it hard to forgive or trust people'.[42]

Another man told us he was sexually abused in a boys' home. He said, 'I have never been able to get these things out of my head. It has been a nightmare for my whole life'.[43]

Dislocation from Country, culture and family

> ... you need to know who your connections are, where your mob comes from and what your mob is about in culture in that area so you can learn it. That is why it's so important.[44]

We have been left in no doubt about the importance of connection to Country, culture and family. When First Nations children with disability are removed from Country and placed in care, continued contact with family, community and return visits to Country can be infrequent. This causes distress and a loss of connection to culture, harming both children and their families.[45]

Mr Thomas said his placement in a children's home took away his connection with culture. He lost contact with his family and his First Nations community.[46] The cultural safety and connection provided through family or kinship care was emphasised to us throughout our work.

Walmajarri woman Marmingee Hand and her husband, Geoff Davis, raised her niece, nephew and two grandsons.[47] In Ms Hand's experience, children removed from remote communities often experience complex trauma:

> You know, it depends on what institution our young people are put in, and there are all sorts of traumas that affect our children. You know, the loss of culture, the loss of connection with family, you know, the home life and trying to adjust, you know, when they do come back, it brings up all this trauma that they may have faced living in institutions or in, you know, someone – in someone else's care.[48]

Ms Hand, whose nephew, Tristan, lives with disability, continued:

> And if – if the supports mechanism is put in place, similar to what we have done for Tristan, you know, really the – the care that we placed around Tristan, I mean, we had to – you know, because we love the young – we love the little – the young man now

> and I guess, you know, keeping my family in place together that he was being raised in – where all his family are, you know, both from my side as well as his father's side. And that he had connection, you know, to his own country here in Fitzroy. And that's the most important things that we need to, you know, have this care for our children. And the best – the best care.[49]

We heard troubling accounts of First Nations children with disability being removed and:

- being denied knowledge of and contact with their families and communities[50]
- being told their families do not want them or are dead[51]
- being restricted from visiting or not able to visit gravely ill family members who had subsequently died[52]
- not being brought to funerals, including their parent's.[53]

Carers and support

We were told of a lack of support for carers of First Nations children with disability from child protection systems.[54]

'Grace' told the Royal Commission she felt as though child protection departments regarded her as a troublemaker.[55] A First Nations grandmother providing kinship care for her grandson with disability described child protection workers as trying to 'reduce you to nothing'.[56] She feels they 'never' respected her.[57]

Carers raising children with suspected disabilities emphasised the importance of early intervention support and comprehensive clinical assessments to obtain correct diagnoses.[58] Some carers believed child protection departments were slow to arrange or reluctant to pay for disability assessment or diagnosis for children in out-of-home care.[59] The Senior Medical Officer at Danila Dilba Health Service, Dr Andrew Webster, observed that carers who are not a 'squeaky wheel' may find it hard to get the child in their care an assessment.[60]

Research commissioned by the Royal Commission described carers' frustration with having to advocate for the children in their care and navigate child protection systems and complex disability assessment procedures to gain support and diagnoses.[61] A carer at Public hearing 25, 'The operation of the NDIS for First Nations people with disability in remote and very remote communities', told us people 'need a degree in the NDIS to be able to navigate it'.[62]

Through commissioned research we heard child protection staff turnover and lack of training for inexperienced staff affected the support given to carers and consequently the children in their care. This contributed to placement breakdown for First Nations children with disability.[63] A kinship carer told us child protection staff were moved on if they became too familiar with a family.[64]

First Nations parents with disability

> I feel like that I have been robbed of being a mother for the last five years. I found interacting with the department very difficult. I still struggle with anxiety and depression, which I have to sort out with my OT [occupational therapist]. I'm still struggling with everything, to the point where just talking about it brings up a lot for me. I was traumatised by it.[65]

First Nations parents face several barriers seeking supports for their own disability or their child's disability. This includes fear of triggering child protection authorities, limited availability of services and lack of culturally safe services.

As discussed in Chapter 2, First Nations communities often fear and mistrust government as a legacy of past policies. First Nations parents told us they fear that identifying their disability status, or that of their child, will result in child protection intervention.[66]

At a community engagement, a family in a remote community said they were too frightened to access help for their child with cerebral palsy because they feared their child would be 'taken' by child protection authorities.[67]

While at Public hearing 8, 'Kate' a mother with an intellectual disability described her distrust of child protection authorities because, she said, they did not help her when she told them she was being sexually abused at school while a ward of the State.[68] Kate has four children, three of whom, she explained, were removed from her care when she was a teenager or in her early twenties.[69] Her youngest child remains in her care. Kate described feeling well supported by the relevant child protection authority with this child.[70]

Government witnesses at Public hearing 8, appropriately acknowledged First Nations people remain fearful and distrustful of child protection systems.[71] Mr Michael Coutts-Trotter, then Secretary of the NSW Department of Communities and Justice, told us 'child protection systems are characterised by fear, fear amongst staff, and fear among the families we work with'.[72] Ms Katherine Alexander, Chief Practitioner, NSW Department of Communities and Justice described First Nations peoples' fear of her department as 'probably our biggest challenge'.[73]

More details concerning First Nations people with disability and housing are in Volume 7, *Inclusive education, employment and housing*

Disability and First Nations status considered a risk

> When you are diagnosed with a disability, I feel that the Department look at you as if you can't cope. I would like to see their attitude towards Aboriginal parents with disabilities change. If I could say one thing, it's to give them a go. Give parents with a disability a go. To actually let them show that they are fit parents. Not to use it to their advantage of, 'Oh you've got a disability so you can't be a parent'. They need to actually say 'right, let's let them show it'.[74]

We have been told for some First Nations parents a formal diagnosis of disability can potentially be identified as a 'risk' factor by child protection authorities.[75] Research shows that child protection systems identify parental disability, particularly mental health or intellectual disability, as a risk factor.[76] This is reflected in policy and practice.

Professor Megan Davis was appointed by then NSW Minister for Family and Community Services to chair an independent review into Aboriginal and Torres Strait Islander children and young people in out-of-home care.[77] Her 2019 report examined a representative sample of 200 case reviews of families. Of this cohort, disability among children and parents was identified for 35 families (18 per cent of cases in the sample).[78] In 24 families (12 per cent of cases), one or both parents had a diagnosed or suspected intellectual disability. In 16 cases (8 per cent of cases), children were identified as having an intellectual or physical disability, and in one case, 'other unspecified disability'.[79] Reviewers identified in the majority of cases:

> there was no evidence that FACS engaged specialist support such as disability support to promote the rights, interests, and wellbeing of these parents, and in some cases the processes that FACS required parents to participate in were specifically identified by reviewers as not being appropriate for the parents given their disability.[80]

The report noted a routine lack of specialist consultation and assessment, and assumptions about parents' intellectual capacity, appeared to contribute to children being removed from their parents.[81]

In submissions and private sessions, First Nations parents with disability told us they believed their cultural background and their disability have been used to characterise their parenting as unfit and provide a basis for removing their children.[82]

A First Nations parent with disability whose children had been removed told us child protection authorities were incapable of seeing parents with disability as ‘people with strengths’.[83] Another parent with disability felt she was treated differently and looked at as though she was ‘dumb and knew nothing’.[84]

At Public hearing 8, we heard First Nations parents with disability may not seek support when they need if for fear of triggering child safety intervention.[85] First Nations mother ‘Ann’ said case workers told her child protection authorities sought guardianship of her son because of her diagnosis of schizophrenia.[86] Ann explained:

> I thought it was very unfair because I didn’t choose it. I felt like that they had not been straight up with me, that they hadn’t told me at the time that I couldn’t look after my son because of my mental illness. I also felt that being Indigenous was another grey mark against my name.[87]

Ms Thelma Schwartz, Principal Legal Officer at Queensland Indigenous Family Violence Legal Service, has observed First Nations mothers with psycho-social disability experience deteriorating mental health when in contact with child protection systems. She told us her clients feel the system is ‘stacked against them to fail’.[88] Ann described being traumatised by her interactions with child protection authorities. Ann said she still struggles with associated anxiety and depression.[89]

Commissioner June Oscar AO told us child protection staff are sometimes influenced by stigma and attitudes about the capacity of First Nations parents with disability. Conscious or unconscious biases about race and disability influence decisions on risk of harm.[90] She said the risk of:

> incompetence and biased assessments on the part of child protection staff, which in turn may lead to child removal, presents a risk of structural violence in and of itself.[91]

5.4. The need for a First Nations approach

The principle of self-determination is well recognised. Exercising the right to self-determination and culture is protective for First Nations families and children with disability.[92] First Nations people with disability and their communities should participate in all decision-making on programs and policies that affect them.[93]

The role of First Nations Community Controlled Organisations

Increasing the involvement of First Nations Community Controlled Organisations in child protection systems allows First Nations people self-determination and ensures culturally safe services and systems.[94] This approach could also be used for First Nations families with disability, leading to earlier diagnosis and improved voluntary uptake of services, which could prevent child protection intervention.[95] We heard that outcomes for First Nations families with disability would be improved by investing in the community-controlled sector to provide support.[96]

Despite the expertise and cultural safety that First Nations Community Controlled Organisations provide, they are under-utilised by child protection systems.[97]

Multiple witnesses told the Royal Commission that community-controlled organisations did not have sufficient funding or were restricted in their funding agreements from filling the gaps in service delivery for First Nations families with disability.[98] We heard ACCOs need more resourcing to provide better disability services to support First Nations families.[99]

The Secretary of the NSW Department of Communities and Justice accepted a significant increase in primary or secondary services provided by First Nations organisations is needed.[100] He said this would require additional investment in ACCOs.[101]

First Nations community participation in the design of early intervention services is particularly critical to create the best practice models for First Nations parents with disability and their families.[102]

For example, in the Fitzroy Valley in Western Australia, the Marninwarntikura Women's Resource Centre's Marulu Unit delivers a range of services to support families and children affected by FASD, including people living with this disorder who have gone on to have children themselves. The Marlu Unit adapted the Triple P Positive Parenting Program to be culturally appropriate, responsive and effective for the parents with whom they engage.[103] Commissioner Oscar AO believes programs such as this are 'effective in decreasing contact with the child protection system by supporting families to manage complex behaviours and challenging situations'.[104]

Diagnosis and screening

First Nations children are entering or in out-of-home care with undiagnosed disability and they remain undiagnosed while there.[105] Multiple witnesses told us existing health checks on entering out-of-home care are not an effective mechanism to ensure children are assessed and diagnosed.[106]

The Secretariat of National Aboriginal and Islander Child Care (SNAICC) and the national campaign to end the over-representation of Aboriginal and Torres Strait Islander children in out-of-home care, Family Matters, stated the lack of access to timely and culturally appropriate assessment is systemic and exists across every jurisdiction in Australia.[107] Witnesses emphasised the significant barriers to accessing these assessments for First Nations children in out-of-home care.[108] We were told an ACCO in Western Australia reported there are always at least 200 First Nations children in out-of-home care on the waitlist for assessments. Some of these children can slip through the gaps because the ACCO cannot get to them fast enough.[109]

We were also told First Nations children in out-of-home care are unlikely to receive an assessment unless external pressure is placed on child protection authorities.[110]

In Dr Webster's experience, there is a 'diagnostic gap' for First Nations children in out-of-home care in the Northern Territory. He stated 'children face significant challenges in accessing assessments'. He explained it is not uncommon to see adult clients who were in out-of-home care as children and 'who clearly have a significant disability, but do not have a diagnosis'.[111]

Despite the critical need for culturally appropriate disability assessment of First Nations children in out-of-home care, there are few culturally and linguistically appropriate assessment tools available.[112] Chief executive officer of SNAICC, Ms Catherine Liddle, stated there are a number of factors for First Nations children in out-of-home care being unable to access timely disability assessments. Those factors include diagnosis being offered through culturally unsafe or inappropriate services.[113]

Lack of cultural safety in assessment and diagnosis

A lack of cultural safety as well as bias in assessment and diagnostic tools can lead to inaccurate assessments and diagnostic errors.[114]

Dr Tracy Westerman AM is a First Nations psychologist specialising in the mental health and psychological assessment of Aboriginal people. At Public hearing 8, she said psychological and cognitive testing and assessment in Australia remains predominantly mono-cultural. It does not adequately account for cultural differences of First Nations people.[115] Dr Westerman explained:

> there is this myriad of cultural factors that actually mean that Aboriginal people are consistently being assessed as having poor parenting capacity.[116]

We have been told of the difference in outcomes and approach between parenting capacity assessments arranged by child protection authorities and those that are organised independently or where a support person is present.[117]

First Nations mother 'Shontaya' gave evidence about her experience of a parenting capacity assessment.[118] She believed 'this was part of the process' to have her children returned.[119] She was assessed as having poor intellectual functioning, which would affect her parenting ability.[120] Shontaya described a range of issues with the assessment process.[121] In particular, she told us she did not understand the instructions during the assessment.[122] She said the parenting capacity assessment took place a week after she had been assaulted by her partner, and she was feeling traumatised from this incident.[123] She did not feel the assessment took into account the impact of this incident, or the positive steps she had taken to engage support services.[124]

With the support of her lawyers, Shontaya organised an assessment with a psychologist who had a lot of experience working with First Nations people.[125] This psychologist conducted an intellectual capacity assessment on Shontaya, which diagnosed her with a mild intellectual disability. The assessment also determined that she had the capacity to learn and parent her children.[126]

We were told the location and timing of parenting capacity assessments are often inappropriate, particularly where they take place close to traumatic events or in locations that are not culturally safe, such as the offices of child protection departments. Witnesses stated that this affects the outcomes of parenting capacity assessments and raises questions about their reliability.[127] We recognise there are a range of factors that may affect the way a parent presents during these assessments, which may in turn have an affect on the outcome.

Parenting capacity assessments that are based on Western concepts of parenting are not culturally appropriate and do not consider the cultural strengths of First Nations peoples, their families and communities. Nor do they consider First Nations approaches to parenting and kinship systems.

When these assessments are not culturally appropriate, they can have a negative effect on First Nations parents with disability. There is a risk culturally inappropriate parenting capacity assessments may incorrectly recommend that a First Nations person with a disability lacks the capacity to parent as a result of their disability, rather than concluding that with appropriate support and services their capacity can increase.

Recommendation 9.1 Culturally appropriate parenting capacity assessments

State and territory governments should work with First Nations child protection services, peak bodies and First Nations people with disability to co-design clear principles and guidelines for parenting capacity assessments for First Nations parents with disability in their jurisdiction, to ensure assessments are culturally appropriate. The principles and guidelines should include:

- best practice standards of cultural competence for practitioners conducting parenting capacity assessments of First Nations parents with disability
- guidance to assist practitioners conducting parenting capacity assessments of First Nations parents with disability to identify and address assessment test errors that may result from an insufficient understanding of how cultural factors affect assessments of parenting capacity
- a requirement that practitioners conducting parenting capacity assessments of First Nations parents with disability complete mandatory training to implement best practice standards of cultural competence, using testing tools that are culturally appropriate and disability appropriate
- establishing a review process to ensure the design and implementation of these standards is consistent across states and territories.

Health checks in out-of-home care

Health checks are not an effective mechanism to ensure that First Nation children with disability in out-of-home care are assessed and diagnosed.[128] They can be mislabelled as naughty, defiant or oppositional without an appropriate assessment.[129] Central Australian Aboriginal Congress has seen children in out-of-home care labelled as having FASD without assessment or investigation of whether or not prenatal alcohol exposure occurred.[130]

Research found children in care are most at risk of receiving an incorrect diagnosis. This can lead to detrimental outcomes and complications throughout life.[131] One carer commented:

> so he’s only [got] 70 per cent cognition but I really do believe the people that assessed him for FASD were mickey mouse. That particular company was run out of Fitzroy Crossing because of their ineffectual assessments, and because the Department of Child Protection use them as the provider of choice … I had enough of that rhetoric from them, that I went to Princess Margaret’s Indigenous team and I said, ‘help me, help me get him assessed’.[132]

Health checks on entry into out-of-home care are not sensitive enough to pick up lower level of disability that is still functionally significant, and are better suited to identifying the need for referrals or the need for a comprehensive assessment.[133] We heard there must be flexibility in the timing of a comprehensive assessment to ensure children are not further traumatised after removal.[134]

The Ages and Stages Questionnaire-Talking about Raising Aboriginal Kids (ASQ-TRAK) is a culturally adapted developmental screening tool designed to identify developmental issues in First Nations children in Australia.[135] It is based on the internationally recognised Ages and Stages Questionnaire.[136] ASQ-TRAK was developed by the University of Melbourne to specifically overcome the lack of appropriate screening tools for First Nations children in Australia.[137] Before ASQ-TRAK was developed, there was no rigorous, objective way to undertake these assessments with a tool specifically validated for these children.[138]

The Ages and Stages Questionnaire is typically used for children until six years of age. ASQ-TRAK is validated for use with children at certain ages, namely: six, nine, 12 and 18 months, and two, three and four years.[139] It screens across five domains of development: communication, gross motor, fine motor, problem solving and personal-social.[140]

A particular benefit of ASQ-TRAK is its ability to be used by people other than doctors, such as trained First Nations staff in community-controlled health organisations. This in turn enables a culturally safe assessment.[141] Dr John Boffa, of Central Australian Aboriginal Congress, considers it ‘almost unethical’ to do a mainstream child health check on a First Nations child without doing an ASQ-TRAK assessment, because it is ASQ-TRAK that will lead to early intervention.[142]

Early identification of developmental delay in children can trigger support,[143] such as Early Childhood Early Intervention (ECEI) plans for children aged under seven.[144] Central Australian Aboriginal Congress expressed hope:

> that through working with families across a range of domains, including assessment and diagnosis of neurodevelopmental disability for those children who need it, that involvement with child protection and out-of-home care will be prevented as much as possible.[145]

Despite the benefits, current Medicare items do not require a culturally validated tool, such as ASQ-TRAK, to be used when conducting routine health checks on First Nations children.[146]

Danila Dilba Health Service believes 'taking a holistic approach to child health by integrating early assessment and therapeutic services into primary health care will achieve the best outcomes for First Nations families and children, including those who are in out-of-home care'.[147] We agree.

South Australia recognises ASQ-TRAK as a 'best-practice screening tool for assessing developmental delay and vulnerabilities among Aboriginal children', including those in out-of-home care.[148] While New South Wales 'is considering its appropriateness and validity for Aboriginal people in different contexts'.[149]

We recognise the demographics and experiences of First Nations children and families vary across Australia. However, we consider state and territory governments should ensure all First Nations children, including those in out-of-home care, particularly those who live in areas where there is a high level of disadvantage and developmental vulnerability are screened using the ASQ-TRAK through a primary health care service.

We recommend all First Nations children up to five years of age going into out-of-home care are screened using the ASQ-TRAK. Where a child is identified as vulnerable on two or more of the five domains of development, that child should be supported by an application for an ECEI plan.

Recommendation 9.2 Ages and Stages Questionnaire-Talking about Raising Aboriginal Kids (ASQ-TRAK)

State and territory governments should ensure all First Nations children up to five years of age coming into out-of-home care are screened using the culturally adapted developmental screening Ages and Stages Questionnaire-Talking about Raising Aboriginal Kids (ASQ-TRAK) tool. Children who are vulnerable in two or more of the five domains of communication, gross motor, fine motor, problem solving, and personal-social should be supported by an application for an Early Childhood Early Intervention plan.

Early intervention and support

A lack of early support for First Nations parents and children with disability can contribute to contact with child protection systems, particularly in remote areas of Australia.

Central Australian paediatric clinical neuropsychologist Ms Hannah Blaine considers ‘it is much more likely’ that a family will be subject of a notification to child protection authorities for neglect where that family does not have appropriate support for their child with disability. This is because, she said, the family ‘can’t meet the care needs of that child because the care needs are higher’. Equitable access to support is required so that ‘the ability to provide the appropriate level of care is not a consideration for children being removed’.[150]

Australia’s state and territory child protection systems focus on investigation of concerns about child welfare. Where risk of harm is identified, statutory intervention by child protection authorities in family life follows. This intervention includes placing children into out-of-home care. This approach was described as ‘reactive’ with ‘limited’ reference to options to support parents to parent and care for children, and to facilitate a safe family environment.[151]

Commissioner Oscar AO considers child protection authorities should be required to provide information to First Nations parents and families on where and how they can access support.[152] Foster carer ‘Grace’ said families should be supported to keep their children. She believes ‘money is thrown at child protection to remove kids, instead of coming alongside the families and helping to keep these families together’.[153]

Several witnesses said access to quality, culturally safe and targeted early intervention services and supports would prevent children being removed and entering the child protection system.[154]

Case study: 'Kate'[155]

> **My baby is two now. We have a good routine – baby is in bed by seven or eight every night. My baby is achieving well above their age in some areas – that is how good they are. We have a game on the iPad where you have letters and numbers, and you've got to line them up. My two year old does it within two seconds. I love watching my child every minute growing up.[156]**

Kate is a First Nations mother of four children. Kate has had multiple diagnoses of disability, including ADHD, low borderline autism, Asperger's syndrome and intellectual disability.[157] Kate was two years old when she was removed from her biological mother and placed in foster care.[158] She became homeless when she was 16.[159] Her first three children were removed from her care in her late teens or early twenties.[160]

Kate was 17 when she became pregnant with her first child to a partner who inflicted episodes of domestic violence on her.[161] Approximately two weeks after her baby was born, and immediately after Kate turned 18, the child was removed from her care.[162] Kate's second and third children were removed from her care from hospital immediately after each of their birth.[163]

Kate's circumstances had changed by the time she became pregnant with her fourth child at 25. She was no longer experiencing domestic violence. Instead, Kate's partner 'is gentle' and 'understands' her. Her partner also lives with disability.[164]

Kate described working together 'from day dot' with child protection authorities throughout her pregnancy with this child, who remains in her care. In Kate's words:

> This time I felt like the Department actually wanted to support my family because I worked with them, and they listened to what I needed … they listened to what I needed and helped me to achieve it.

Endnotes

1 For example, Exhibit 8-24.4, IND.0001.0004.0001, p 5; Exhibit 8-26.15, EXP.0055.0001.0001, p vi.
2 Exhibit 8-24, ‘Statement of Richard Weston’, 23 November 2020, at [52].
3 In South Australia, responsibility for collecting and analysing data is shared across multiple agencies (see Submission by South Australian Government in response to Counsel Assisting’s submissions in Public hearing 8, 21 December 2021, SUB.M.0017.0001.0567, pp 7–8).
4 Exhibit 16-42, DRC.9999.0065.0001, p. 2.
5 Exhibit 8-27, ‘Statement of Jo Wood’, 26 October 2020, at [question 2]; Exhibit 8-28, ‘Statement of Leonie Warburton’, 5 October 2020, at [23–24]; Exhibit 8-28.2, ‘Further statement of Leonie Warburton’, 28 October 2020, at [4b]; Exhibit 8-29 ‘Statement of Michael Pervan’, 27 October 2020, at [5–6]; Exhibit 831, ‘Statement of Michelle Andrews’, 6 October 2020, at [MA1-B3]; Exhibit 8-19, ‘Statement of Catherine Taylor’, 22 October 2020, at [44]; Exhibit 8-8, ‘Statement of Meegan Crawford’, 23 October 2020, at [27].
6 Exhibit 8-27, ‘Statement of Jo Wood’, 26 October 2020, at [question 1]; Exhibit 8-28, ‘Statement of Leonie Warburton’, 5 October 2020, at [9–13]; Exhibit 8-28.2, ‘Further Statement of Leonie Warburton’, 28 October 2020, at [4]; Exhibit 8-30, ‘Statement of Shane Wilson’, 16 October 2020, at [7–10]; Exhibit 8-31, ‘Statement of Michelle Andrews’, 6 October 2020, at [MA1-B1]; Exhibit 8-19, ‘Statement of Catherine Taylor’, 22 October 2020, at [42–43]; Exhibit 8-8, ‘Statement of Meegan Crawford’, 23 October 2020, at [26–27]; Exhibit 8-14, ‘Statement of Michael Coutts-Trotter’, 28 October 2020, at [31–34]; See also, Exhibit 8-29, ‘Statement of Michael Pervan’, 27 October 2020, at [5]. Mr Pervan stated that in Tasmania the department does not routinely collect or record the First Nations status of parents ‘in a way that it could reliably statistically reported [sic] for all parents in contact with child protection services’. However, he noted that this information may still be captured in data fields in its client management system or in case notes, but not in a systematic manner.
7 For example, Exhibit 8-19, ‘Statement of Catherine Taylor’, 22 October 2020, at [42]; Exhibit 8-28, ‘Statement of Leonie Warburton’, 5 October 2020, at [11]; Exhibit 8-14, ‘Statement of Michael CouttsTrotter, 28 October 2020, at [32–33].
8 For example, Exhibit 8-27, ‘Statement of Jo Wood’, 26 October 2020, at [questions 1 and 2]; Exhibit 8-31, ‘Statement of Michelle Andrews’, 6 October 2020, at [MA1-B2].
9 Submission by the State of New South Wales in response to Counsel Assisting’s submissions in Public hearing 8, 19 November 2021, SUBM.0017.0001.0509, p 21.
10 Submission by State of South Australia in response to Counsel Assisting’s submissions in Public hearing 8, 21 December 2021, SUB.M.0017.0001.0567, pp 7–8.
11 Exhibit 8-27, ‘Statement of Jo Wood,’ 26 October 2020, at [question 2g]; Exhibit 8-28, ‘Statement of Leonie Warburton’, 5 October 2020, at [15]; Exhibit 8-29, ‘Statement of Michael Pervan,’ 27 October 2020, at [4-5]; Exhibit 8-30, ‘Statement of Shane Wilson,’ 16 October 2020, at [19]; Exhibit 8-31, ‘Statement of Michelle Andrews,’ 6 October 2020, at [MA1-B2g]; Exhibit 8-19, ‘Statement of Catherine Taylor,’ 22 October 2020, at [44-45]; Exhibit 8-8, ‘Statement of Meegan Crawford,’ 23 October 2020, at [30]; Exhibit 8-14, ‘Statement of Michael Coutts-Trotter,’ 28 October 2020, at [51].
12 Exhibit 8-24, ‘Statement of Richard Weston’, 23 November 2020, at [52]; Transcript, Richard Weston, Public hearing 8, 27 November 2020, P-429 [35–42].
13 Submission by the Australian Government in response to Counsel Assisting’s submissions in Public hearing 16, 22 December 2021, SUBM.0017.0001.0593, p 3.
14 Transcript, Dana Clarke, Public hearing 8, 27 November 2020, P-404 [40]–P-405 [6].
15 See submission of Counsel Assisting the Royal Commission following Public hearing 8, pp 50–69; Submission of Counsel Assisting the Royal Commission following Public hearing 16, pp 122–45.
16 Submission of Counsel Assisting the Royal Commission following Public hearing 8, p 66 [210(a)]; Submission of Counsel Assisting the Royal Commission following Public hearing 16, p 142 [468].
17 Name withheld, Submission, 16 February 2021.
18 Exhibit 8-21, ‘Statement of Candice Butler’, 16 November 2020, at [17]; Exhibit 8-3, ‘Statement of June Oscar AO’, 17 November 2020, at [70–81]; Exhibit 8-24, ‘Statement of Richard Weston’, 23 November 2020, at [22]; Queensland Aboriginal and Islander Health Council, Submission in

response to *Health care for people with cognitive disability issues paper*, ISS.001.00136, 4 June 2020, p 11.

19 Name changed, private session, ‘Lexie’; Kathy Kendall, Submission in response to *Group homes issues paper*, 3 March 2020, ISS.001.00063, p 4; Aboriginal Family Legal Services, Submission, 9 July 2021, SUB.100.01139.

20 Exhibit 11-33.1, ‘Statement of Justen Thomas’, 29 September 2020, at [8].

21 Transcript, Justen Thomas, Public hearing 11, 25 February 2021, P-599 [32–34], P-600 [23–26].

22 Exhibit 11-33.1, ‘Statement of Justen Thomas’, 29 September 2020, at [8].

23 Name changed to protect identity.

24 Exhibit 11-1.4, NSW.0024.0001.0166, p 1.

25 Exhibit 11-1.10, NSW.0024.0001.3702, p 1.

26 Transcript, ‘Melanie’, Public hearing 11, 16 February 2021, P-35 [44]–P-36 [1].

27 Transcript, ‘IL’, Public hearing 16, 17 September 2021, P-26 [22–23].

28 Transcript, ‘IL’, Public hearing 16, 17 September 2021, P-29 [46]–P-31 [12].

29 Transcript, ‘IL’, Public hearing 16, 17 September 2021, P-30 [11–17], [22–24].

30 Name changed to protect identity.

31 Name changed to protect identity.

32 Transcript, ‘Grace’, Public hearing 16, 20 September 2021, P-93 [29–33]. Names changed to protect identity.

33 Exhibit 16-7, ‘Statement of ‘Grace’’, 15 September 2021, at [77–78].

34 Name changed, private session, ‘Brooks’.

35 Royal Commission community engagement, Queensland, February 2021.

36 Name changed, private session, ‘Wayne’.

37 Phillipa (Pippa) Krause, Submission, 4 June 2021, SUB.500.00117.

38 Phillipa (Pippa) Krause, Submission, 4 June 2021, SUB.500.00117.

39 Kathy Kendall, Submission in response to *Group homes issues paper*, 3 March 2020, ISS.001.00063, p 4.

40 Name withheld, Submission, 29 April 2021; Name withheld, Submission, 22 April 2021; Name withheld, Submission, 29 April 2021; Name withheld, Submission, 2 March 2021.

41 Name withheld, Submission, 29 April 2021; Name withheld, Submission, 14 May 2021.

42 Name withheld, Submission, 14 May 2021.

43 Name withheld, Submission, 29 April 2021.

44 Transcript, Aunty Maggie, Public hearing 16, 24 September 2021, P-497 [13–15].

45 Transcript, ‘IL’, Public hearing 16, 17 November 2021, P-34 [45]–P-55 [2]; Transcript, Aunty Winnie, Public hearing 16, 17 November 2021, P-79 [5]–P-80 [20].

46 Transcript, Justen Thomas, Public hearing 11, 25 February 2021, P-599 [36]–P-600 [8], [31–33].

47 Exhibit 25-40, ‘Statement of Marmingee Hand’, 4 July 2022, at [8–9]; Exhibit 25-41, ‘Statement of Geoff Davis’, 15 June 2022, at [4].

48 Transcript, Marmingee Hand, Public hearing 25, 13 July 2022, P-180 [24–28].

49 Transcript, Marmingee Hand, Public hearing 25, 13 July 2022, P-180 [33–40].

50 Name changed, private session, ‘Wayne’.

51 Name changed, private session, ‘Brooks’.

52 Jocelyn Jones, Lynn Roarty, John Gilroy, Juliet Brook, Mandy Wilson, Cathy Garlett, Hannah McGlade, Robyn Williams & Helen Leonard, *Wangkiny Yirra ‘Speaking Up’ Project: First Nations women and children with disability and their experiences of family and domestic violence,* Report prepared for the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, June 2023, p 101.

53 Transcript, Aunty Winnie, Public hearing 16, 17 September 2020, P-77 [16–26].

54 Transcript, Doreen McCormack, Public hearing 16, 17 September 2021, P-22 [41–46]; Transcript, ‘Grace’, Public hearing 16, 20 September 2021, P-98 [25–35]; Transcript, Aunty Audrey, Public hearing 16, 19 September 2021, P-40 [45]–P-41 [1], P-49 [25–29].

55 Exhibit 16-7, ‘Statement of ‘Grace’’, 15 September 2021, at [47].

56 Transcript, Aunty Audrey, Public hearing16, 17 September 2021, P-41 [38].

57 Transcript, Aunty Audrey, Public hearing16, 20 September 2021, P-42 [19].

58 Name changed, private session, ‘Rosalie’.

59 Name changed, private session, ‘Rosalie’.

60 Exhibit 16-11, ‘Statement of Dr Andrew Webster’, 15 September 2021, at [37].

61 Jocelyn Jones, Lynn Roarty, John Gilroy, Juliet Brook, Mandy Wilson, Cathy Garlett, Hannah McGlade, Robyn Williams & Helen Leonard, *Wangkiny Yirra 'Speaking Up' Project: First Nations women and children with disability and their experiences of family and domestic violence*, Report prepared for the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, June 2023, pp 124–126.

62 Transcript, 'Joan', Public hearing 25, 11 July 2022, P-49 [33].

63 Jocelyn Jones, Lynn Roarty, John Gilroy, Juliet Brook, Mandy Wilson, Cathy Garlett, Hannah McGlade, Robyn Williams & Helen Leonard, *Wangkiny Yirra 'Speaking Up' Project: First Nations women and children with disability and their experiences of family and domestic violence*, Report prepared for the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, June 2023, p 130.

64 Transcript, Auntie Audrey, Public hearing 16, 21 November 2021, P-43 [36–40].

65 Exhibit 8-1, 'Statement of Ann', 23 November 2020, at [89].

66 Exhibit 8-3, 'Statement of June Oscar AO', 17 November 2020, at [51]; Exhibit 8-011, Statement of Kenn Clift, 17 November 2020, at [16]; Exhibit 16-30, 'Joint statement of Mr Paul Gray and Ms Catherine Liddle', 20 September 2021, at [20]; Rosalie Larara, Submission, 22 July 2021, SUB.001.01181, p 3; Queensland Aboriginal and Torres Strait Islander Child Protection Peak, Submission in response to *The experience of First Nations people with disability in Australia issues paper*, 16 October 2020, ISS.001.00492, p 13; First Peoples Disability Network, Submission in response to the *Promoting inclusion issues paper*, 4 June 2021, ISS.001.00651, p 8; Name changed, private session, 'Jaylee'. [PS Summary PS/2020-0582]; Name changed, private session, 'Destiny'.

67 Royal Commission community forum, Victoria, 2021; Royal Commission community forum, Broome, 2021; Royal Commission community forum, Kimberley, 2021.

68 Exhibit 8-10, 'Statement of 'Kate'', 23 November 2020, at [19].

69 Exhibit 8-10, 'Statement of 'Kate'', 23 November 2020, at [3].

70 Exhibit 8-10, 'Statement of 'Kate'', 23 November 2020, at [40–41].

71 Transcript, Michael Coutts-Trotter, Public hearing 8, 25 November 2020, P-256 [21–25]; Transcript, Katherine Alexander, Public hearing 8, 25 November 2020, P-269 [22]; Transcript, Meegan Crawford, Public hearing 8, 24 November 2020, P-169 [40]–P-170 [14].

72 Transcript, Michael Coutts-Trotter, Public hearing 8, 25 November 2020, p 254 [26–27].

73 Transcript, Katherine Alexander, Public hearing 8, 25 November 2020, p 269 [22].

74 Exhibit 8-10, 'Statement of 'Kate'', 23 November 2020, at [47(d)].

75 Transcript, April Lawrie, Public hearing 8, 26 November 2020, P-343 [22–46]; Transcript, Daryl Higgins, Public hearing 8, 24 November 2020, P-141 [7–12]; Exhibit 8-23, 'Statement of Olivia King', 23 November 2020, at [83].

76 Isabel Grant, Judith Mosoff, Susan B Boyd & Ruben Lindy, 'Intersecting challenges: Mothers and child protection law in BC', (2017), vol 50 (2), *UBC Law Review*, pp 435, 468; Judith Mosoff, 'Motherhood, madness and law', (1995), vol 45 (2), *University of Toronto Law Journal*, pp 107, 111; Rachel Patterson, 'The child welfare hyper surveillance state: Reimagining supporting parents with mental illnesses in 1028 hearings', (2020), vol 48 (2), *Fordham Urban Law Journal*, pp 545, 583; Victorian Aboriginal Child Care Agency, Submission in response to *The experience of First Nations people with disability in Australia issues paper*, 10 November 2020, ISS.001.00486, p 10.

77 Megan Davis, *Family is culture: Independent review into Aboriginal and Torres Strait Islander children and young people in out-of-home care in New South Wales*, Final report, October 2019, p xi.

78 Megan Davis, *Family is culture: Independent review into Aboriginal and Torres Strait Islander children and young people in out-of-home care in New South Wales*, Final report, October 2019, p 175.

79 Megan Davis, *Family is culture: Independent review into Aboriginal and Torres Strait Islander children and young people in out-of-home care in New South Wales*, Final report, October 2019, pp 175–176.

80 Megan Davis, *Family is culture: Independent review into Aboriginal and Torres Strait Islander children and young people in out-of-home care in New South Wales*, Final report, October 2019, p 175.

81 Megan Davis, *Family is culture: Independent review into Aboriginal and Torres Strait Islander children and young people in out-of-home care in New South Wales*, Final report, October 2019, p 176.

82 Name changed, private session, ‘Xanthe’; Name changed, private session, ‘Destiny’; Name changed, private session, ‘Rosalie’; Name withheld, Submission, 1 October 2021, SUB.001.01312, p 1; Queensland Office of the Public Guardian, Submission in response to the *Violence and abuse of people with disability at home issues paper*, 23 April 2021, ISS.001.00624, p 17.

83 Name withheld, Submission, 1 October 2021.

84 Name changed, private session, ‘Xanthe’.

85 For example, Exhibit 8-2, ‘Statement of Christine May’, 19 November 2020, at [50]; Exhibit 8-24, ‘Statement of Richard Weston’, 22 November 2020, at [40].

86 Exhibit 8-1, ‘Statement of Ann’, 23 November 2020, at [65], [67].

87 Exhibit 8-1, ‘Statement of Ann’, 23 November 2020, at [67].

88 Exhibit 8-6, ‘Statement of Thelma Schwartz’, 20 November 2020, at [32].

89 Exhibit 8-1, ‘Statement of Ann’, 23 November 2020, at [89].

90 Exhibit 8-3, ‘Statement of June Oscar AO’, dated 17 November 2020, at [139–140]

91 Exhibit 8-3, ‘Statement of June Oscar AO’, dated 17 November 2020, at [149].

92 Transcript, Tracy Westerman, Public hearing 8, 24 November 2020, P-88 [23–38]; Susan Baidawi, Rubini Ball, Robyn Newitt, Lena Turnbull, Gayatri Kembhavi-Tam, Scott Avery, Rosemary Sheehan & Jade Purtell, *Care criminalisation of children with disability in child protection systems*, Report prepared for the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, May 2023, p 180.

93 Exhibit 8-3, ‘Statement of June Oscar AO’, 17 November 2020, at [22]; Transcript, Dana Clarke, Public hearing 8, 27 November 2020, P-399 [18–25]; Transcript, Kumalie Riley, Public hearing 16, 17 November 2021, P-20 [44–47]–P-21 [14–18], P-24 [4–6]; Transcript, Patricia Turner AM, Public hearing 25, 14 July 2022, P319 [35–37]; Victorian Aboriginal Child Care Agency, Submission in response to *The experiences of First Nations people with disability in Australia issues paper*, 11 October 2020, ISS.001.00486, p 16.

94 Exhibit 8-18, ‘Statement of Commissioner April Lawrie’, 19 November 2020, at [34].

95 Exhibit 8-18, ‘Statement of Commissioner April Lawrie’, 19 November 2020, at [49].

96 Transcript, Richard Weston, Public hearing 8, 27 November 2020, P-428 [22–27], P-428 [45–46], P-432 [30–36].

97 Exhibit 8-21, ‘Statement of Candice Butler’, 16 November 2020, at [63].

98 Exhibit 8-7, ‘Statement of Professor Daryl Higgins’, 12 November 2020, at [54–55]; Exhibit 8-23, ‘Statement of Olivia King’, 23 November 2020, at [38], [91]; Transcript, Candice Butler, Public hearing 8, 27 November 2020, P-401 [21–36].

99 Exhibit 16-31, ‘Statement of Catherine Liddle’, 23 September 2021, at [88]; Exhibit 8-3, ‘Statement of June Oscar AO’, 17 November 2020, at [56]; Transcript, Candice Butler, Public hearing 8, 27 November 2020, P-401 [25–30].

100 Transcript, Michael Coutts-Trotter, Public hearing 8, 25 November 2020, P-285 [44–46].

101 Transcript, Michael Coutts-Trotter, Public hearing 8, 25 November 2020, P-286 [27–30].

102 Exhibit 8-24, ‘Statement of Richard Weston’, 23 November 2020, at [84]; Exhibit 8-7, ‘Statement of Professor Daryl Higgins’, 12 November 2020, at [67]; Transcript, Daryl Higgins, Public hearing 8, 24 November 2020, P-138 [39–46], P-139 [1–5].

103 Transcript, June Oscar, Public hearing 8, 23 November 2020, P-69 [44]–P-70 [13]; Exhibit 8-3, ‘Statement June Oscar’, 17 November 2020, at [213–15].

104 Exhibit 8-3, ‘Statement June Oscar AO’, 17 November 2020, at [216].

105 Exhibit 16-33, ‘Statement of Maeve Kennedy’, 17 September 2021, at [40]; Exhibit 16-30, ‘Joint statement of Mr Paul Gray and Ms Catherine Liddle’, 20 September 2021, at [45], [48]; Exhibit 16-11, ‘Statement of Dr Andrew Webster’, 15 September 2021, at [34–35], [37], [55–56]; Exhibit 16-31, ‘Statement of Catherine Liddle’, 23 September 2021, at [31]; Exhibit 16-8, ‘Joint statement of Donna Ah Chee and Dr John Boffa’, 17 September 2021, at [37]; Exhibit 16-10, ‘Joint statement of Ms Amelia Patterson and Ms Hannah Blaine’, 17 September 2021, at [17]; Transcript, Amelia Paterson, Public hearing 16, 20 September 2021, P-131 [10]; Aboriginal Family Legal Services, Submission, 9 July 2021, SUB.100.01435, p 5..

106 Exhibit 16-33, ‘Statement of Maeve Kennedy’, 17 September 2021, at [44]; Exhibit 16-11, ‘Statement of Dr Andrew Webster’, 15 September 2021, at [48]; Exhibit 16-9, ‘Joint statement of Ms Amelia Paterson and Ms Hannah Blaine’, 17 September 2021, at [23]; Exhibit 16-30, ‘Joint statement of Mr Paul Gray and Ms Catherine Liddle’, 20 September 2021, at [52].

107 Exhibit 16-30, ‘Joint Statement of Mr Paul Gray and Ms Catherine Liddle’, 20 September 2021, [51].

108 Exhibit 16-30, ‘Joint statement of Mr Paul Gray and Ms Catherine Liddle’, 20 September 2021, at [56] and [61]; Exhibit 16-31, ‘Statement of Ms Catherine Liddle, 23 September 2021, at [36–38]; Exhibit 16-11, ‘Statement of Dr Andrew Webster, 15 September 2021, [47–72]; Exhibit 16-32, ‘Statement of Sharynne Hamilton’, 15 September 2021 at [30–36]; Exhibit 16-33, ‘Statement of Ms Maeve Kennedy’, 17 September 2021, at [91–96].

109 Exhibit 16-30, ‘Joint statement of Mr Paul Gray and Ms Catherine Liddle’, 20 September 2021, at [57].

110 Exhibit 16-30, ‘Joint statement of Mr Paul Gray and Ms Catherine Liddle’, 20 September 2021, at [51].

111 Exhibit 16-11, ‘Statement of Dr Andrew Webster’, 15 September 2021, at [40].

112 Exhibit 16-30, ‘Joint statement of Mr Paul Gray and Ms Catherine Liddle’, 20 September 2021 at [56–57]; Transcript, Dr Andrew Webster, Public Hearing 16, 23 September 2021, P-168 [47]–P-169 [5].

113 Exhibit 16-31, ‘Statement of Ms Catherine Liddle’, 23 September 2021, at [35].

114 Exhibit 16-11, ‘Statement of Dr Andrew Webster’, 15 September 2021, at [53]; Exhibit 16-31, ‘Statement of Ms Catherine Liddle’, 23 September 2021, at [36].

115 Exhibit 8-4.1, ‘Statement of Tracy Westerman’, 24 November 2020, at [3], [30].

116 Transcript, Tracy Westerman, Public hearing 8, 24 November 2020, P-97 [11–13].

117 Exhibit 8-12, ‘Statement of Julia Wren’, 19 November 2020, at [53–55]; Exhibit 8-23, ‘Statement of Olivia King’, 23 November 2020, at [82].

118 Name changed to protect identity.

119 Exhibit 8-16, ‘Statement of ‘Shontaya’’, 17 November 2020, at [85].

120 Exhibit 8-16, ‘Statement of ‘Shontaya’’, 17 November 2020, at [93]; Transcript, ‘Shontaya’, Public hearing 8, 26 November 2020, P-310-311 [35-6]; Exhibit 8-16.6, SAG.0001.0001.2545_E.

121 Exhibit 8-16, ‘Statement of ‘Shontaya’’, 17 November 2020, at [87–106]; Transcript, ‘Shontaya’, Public hearing 8, 26 November 2020, at P-308–309 [31–34].

122 Exhibit 8-16, ‘Statement of ‘Shontaya’’, 17 November 2020, at [88]; Transcript, ‘Shontaya’, Public hearing 8, 26 November 2020, P-308 [31–46].

123 Exhibit 8-16, ‘Statement of ‘Shontaya’’, 17 November 2020, at [87], [89].

124 Exhibit 8-16, ‘Statement of ‘Shontaya’’, 17 November 2020, at [89], [98], [104], [106].

125 Exhibit 8-16, ‘Statement of ‘Shontaya’’, 17 November 2020, at [120–121]; Transcript, ‘Shontaya’, Public hearing 8, 26 November 2020, P-314 [36–40], P-315 [25-27]; Exhibit 8-16.27, SAG.0001.0001.4065_E.

126 Exhibit 8-16, ‘Statement of ‘Shontaya’’, 17 November 2020, at [121–122]; Transcript, ‘Shontaya’, Public hearing 8, 26 November 2020, P-315 [31–34].

127 Exhibit 8-12, ‘Statement of Julia Wren’, 19 November 2020, at [53–55], [65]; Transcript, Julia Wren, Public hearing 8, 25 November 2020, P-227 [12–16], P-230 [41–47]; Exhibit 8.16, ‘Statement of ‘Shontaya’’, 17 November 2020, at [87–106]; Transcript, ‘Shontaya’, Public hearing 8, 26 November 2020, P-307–P-313; Exhibit 8.10, ‘Statement of ‘Kate’’, 23 November 2020, at [25]; Transcript, ‘Kate’, Public hearing 8, 25 November 2020, P-206–07 [43–45].

128 Exhibit 16-9, ‘Joint statement of Ms Amelia Paterson and Ms Hannah Blaine’, 17 September 2021, at [23]; Exhibit 16-30, ‘Joint statement of Mr Paul Gray and Ms Catherine Liddle’, 20 September 2021, at [52–55]; Exhibit 16-33, ‘Statement of Maeve Kennedy’, 17 September 2021, at [44]; Exhibit 16-11, ‘Statement of Dr Andrew Webster’, 15 September 2021, at [48–50].

129 Transcript, Hannah Blaine, Public hearing 16, 20 September 2021, P-126 [34–37].

130 Transcript, Hannah Blaine, Public hearing 16, 20 September 2021, P-131 [15–21].

131 Jocelyn Jones, Lynn Roarty, John Gilroy, Juliet Brook, Mandy Wilson, Cathy Garlett, Hannah McGlade, Robyn Williams & Helen Leonard, *Wangkiny Yirra ‘Speaking Up’ Project: First Nations women and children with disability and their experiences of family and domestic violence*, Report prepared for the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, June 2023, p 127.

132 Jocelyn Jones, Lynn Roarty, John Gilroy, Juliet Brook, Mandy Wilson, Cathy Garlett, Hannah McGlade, Robyn Williams & Helen Leonard, *Wangkiny Yirra ‘Speaking Up’ Project: First Nations women and children with disability and their experiences of family and domestic violence*, Report prepared for the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with

Disability, June 2023, p 127.
133 Exhibit 16-9, ‘Joint statement of Ms Amelia Paterson and Ms Hannah Blaine’, 17 September 2021, at [23].
134 Transcript, Dr Andrew Webster, Public hearing 16, 23 September 2021, P-166 [5–10].
135 Transcript, John Boffa, Public hearing 16, 20 September 2021, P-117 [27–44].
136 Transcript, John Boffa, Public hearing 16, 20 September 2021, P-117 [27–31].
137 Exhibit 16-11, ‘Statement of Dr Andrew Webster’, 15 September 2021, at [54].
138 Exhibit 16-8, ‘Joint statement of Donna Ah Chee and Dr John Boffa’, 17 September 2021 at [38]; Transcript, John Boffa, Public hearing 16, 20 September 2021, P-111 [40].
139 Transcript, John Boffa, Public hearing 16, 20 September 2021, P-117 [27–42].
140 ‘What is the ASQ-TRAK’, *Strong kids, Strong future*, web page. <www.strongkidsstrongfuture.com.au/asqtrak/>
141 Transcript, Dr Andrew Webster, Public hearing 16, 20 September 2021, P-169 [11–32]; Exhibit 16-8, ‘Joint statement of Donna Ah Chee and Dr John Boffa’, 17 September 2021, at [37–39], [75].
142 Transcript, John Boffa, Public hearing 16, 20 September 2021, P-117 [40–44].
143 Transcript, John Boffa, Public hearing 16, 20 September 2021, P-119 [13–32].
144 Transcript, Hannah Blaine, Public hearing 16, 20 September 2021, P-117 [7–12]; Exhibit 16-8, ‘Joint statement of Donna Ah Chee and Dr John Boffa’, 17 September 2021, at [37–39].
145 Exhibit 16-8, ‘Joint statement of Donna Ah Chee and Dr John Boffa’, 17 September 2021, at [72].
146 Transcript, John Boffa, Public hearing 16, 20 September 2021, P-119 [34–47].
147 Transcript, Dr Andrew Webster, Public hearing 16, 23 September 2021, P-166, [73].
148 Submission of the State of South Australia in response to Counsel Assisting’s submissions following Public hearing 16, 4 February 2022, at [72].
149 Submission of the State of New South Wales in response to Counsel Assisting’s submissions following Public hearing 16, 24 December 2021, at [16].
150 Transcript, Hannah Blaine, Public hearing 16, 20 September 2021, P-124 [33–38]. See also Exhibit 821, ‘Statement of Candice Butler’, 16 November 2020, at [21–22].
151 Exhibit 8-7, ‘Statement of Professor Daryl Higgins’, 12 November 2020, at [11–13]. See also Exhibit 8.26, ‘Statement of Professor Clare Tilbury’, 20 November 2020, at [38–40].
152 Exhibit 8-3, ‘Statement June Oscar AO’, 17 November 2020, at [125].
153 Transcript, ‘Grace’, Public hearing 16, 20 September 2021, P-101 [30–33].
154 Transcript, April Lawrie, Public hearing 8, 26 November 2020, P-340 [26]–P-341 [24]; Transcript, Natalie Lewis, Public hearing 8, 26 November 2020, P-341 [33–38]; Exhibit 8-21, ‘Statement of Candice Butler’, 16 November 2020, at [21], [52].
155 Name changed to protect identity.
156 Exhibit 8-10, ‘Statement of ‘Kate’’, 23 November 2020, at [42].
157 Exhibit 8-10, ‘Statement of ‘Kate’’, 23 November 2020, at [4]; Transcript, ‘Kate’, Public hearing 8, 25 November 2020, P-195 [40].
158 Exhibit 8-10, ‘Statement of ‘Kate’’, 23 November 2020, at [8]; Transcript, ‘Kate’, Public hearing 8, 25 November 2020, P-196 [21–24].
159 Exhibit 8-10, ‘Statement of ‘Kate’’, 23 November 2020, at [14]; Transcript, ‘Kate’, Public hearing 8, 25 November 2020, P-200 [10–14].
160 Exhibit 8-10, ‘Statement of ‘Kate’’, 23 November 2020, at [3]; Transcript, ‘Kate’, Public hearing 8, 25 November 2020, P-195 [16–24].
161 Exhibit 8-10, ‘Statement of ‘Kate’’, 23 November 2020, at [15]; Transcript, ‘Kate’, Public hearing 8, 25 November 2020, P-200 [37–44], P-201 [1–18], [35–43].
162 Exhibit 8-10, ‘Statement of ‘Kate’’, 23 November 2020, at [20].
163 Exhibit 8-10, ‘Statement of ‘Kate’’, 23 November 2020, at [28], [31–32]; Transcript, ‘Kate’, Public hearing 8, 25 November 2020, P-207 [30–34], P-208 [1–10].
164 Exhibit 8-10, ‘Statement of ‘Kate’’, 23 November 2020, at [36].

6. Criminal justice

Key points

- The experiences of First Nations people with disability in their interactions with the justice system are poorly documented. Our inquiry provided the opportunity to remedy this deficiency.
- The youngest children in the justice system are most often First Nations children, those with disability, and those involved in child protection systems.
- First Nations adults, children and young people with disability experience racist and ableist attitudes, physical violence, and physical and chemical restraints in criminal justice settings.
- Proper cultural support can help First Nations people with disability achieve better outcomes during and after engagement with criminal justice systems.

6.1. Introduction

First Nations people in Australia have a long and complex history with the criminal justice system. This history is well documented in research, countless reports and inquiries. What is not documented is the experience of First Nations people with disability and their interactions with the justice system. Our inquiry provided the opportunity to examine this in detail.

In this chapter, we give voice to what First Nations people with disability across Australia shared with us about criminal justice systems through public hearings, private sessions, submissions and our engagement activities.

Our detailed analysis of criminal justice and people with disability, including our recommendations, is in Volume 8, *Criminal justice and people with disability*. There we establish that people with disability are significantly over-represented at all stages of the criminal justice process in Australia. Further, we establish First Nations people are disproportionately represented in adult prisons and youth detention centres when compared with non-Indigenous Australians.

As we explain in Volume 8, there are limitations to determining the true number of people with disability in contact with criminal justice systems. Given the high rates of disability among First Nations people in the general population, it is reasonable to expect these rates are similarly reflected among First Nations people in contact with criminal justice systems. What is clear is the hidden national crisis that is the proportion of First Nations people with cognitive disability in custody, particularly youth detention.

6.2. Pathways to contact with criminal justice systems

> I ended up running away from the kids' homes to try and go back home. I became homeless. When I was homeless, I started hanging out with the wrong crowd. I started shoplifting, which led to arrests and then outstanding warrants.[1]

We commissioned research focused on children with disability at the intersection of child protection and youth justice systems. It concluded 'neurodisability and complex trauma' are the 'most common disabilities seen among children in child protection systems who experience criminalisation'.[2] It observed that people who encounter child protection systems often experience worse outcomes when it comes to the youth and adult justice systems.[3]

The research identified that the youngest children in the justice system are most often First Nations children, those with neurodisability, and those who are involved in child protection systems.[4] This is reflected in the experience of a young person identified as 'IL', who had been in care since he was aged four or five, and in and out of jail since he was 10.[5]

In Chapter 5, we referred to Justen Thomas's experience in child protection. He lives with epilepsy and intellectual disability, and is an advocate for people with intellectual disability.[6] When he was 13 or 14 years old, he started getting into trouble. He was unaware of his trauma and intellectual disability.[7] Like many First Nations people with disability who shared their experiences with us, he found himself cycling from child protection into youth detention.

When a teen, he absconded from a children's home and became homeless. He then came to the attention of law enforcement, ultimately breaching community orders, which he did not understand.[8] He explained:

> No one explained these orders to me. I did not understand what I could and couldn't do. The cops also used to pick on me when I was sleeping on the train. They would give me fines and I would tear them up. I ended up with a lot of fines that I could not pay.[9]

He 'spent a long time sitting in juvenile centres' while waiting for a place in a refuge so he could be released on bail.[10] He continued:

> When I was aged 16 I went to live in Victoria for a while to try and break the cycle I was in. I came back to Sydney when I was 18. I started staying in boarding houses. I kept going back to prison for things like property theft and unpaid fines.[11]

Melanie was removed from her biological mother when she was aged four. At that time, there were indications of sexual abuse.[12] She was placed in foster care and sexually abused. Melanie was seven when she was deemed 'not fosterable' and placed in institutional care, where she was sexually, physically and psychologically abused while living in institutions.[13] Between the ages of 12 and 16, Melanie was again placed in foster care, this time with a family that showed her 'care, love, and kindness'.[14]

However, Melanie continued to experience difficulties. She was expelled from school and went 'in and out of institutions'.[15] At 16 years of age she committed an act of serious violence and was charged with attempted murder. She was detained in juvenile detention, where she committed another serious act of violence that resulted in the death of a staff member. At 17, Melanie was transferred from juvenile detention to an adult prison.[16] We detail Melanie's experiences in detention later in this chapter, and in Volume 8.

Mr Geoffrey Thomas lives with cognitive impairment, psychosocial disability, chronic depression, suicidal ideation, acute anxiety, post-traumatic stress disorder, and attention deficit disorder. He spent time in a boys' home when he was aged 16. He has been to prison six times, but not since 2003.[17] He described negative interactions with police and mental health services over a period of more than 40 years.[18] He reminded us that while he does not deny his criminal history, that is not his full story.[19]

He described experiencing significant family violence as a child.[20] He attended 13 primary schools and when he started high school, he could neither read nor write. He left home as a teenager and left school before completing year 10. At 15, he was first arrested.

Mr Thomas linked his involvement with the criminal justice system with trauma that began early in life:

> I think my childhood experiences were the beginning of the breakdown of trust between me and authority. So many of the adults in my life, and people in authority, like teachers and the police, could not be trusted.[21]

Childhood trauma was a theme among First Nations people with disability who shared their experiences about criminal justice systems with us. Dr Marshall Watson, Consultant Child and Adolescent Forensic Psychiatrist, observed that 'developmental trauma affects the majority if not all young First Nations people in custody'.[22]

6.3. Harmful conditions and interactions

> I have had a bad upbringing but I'm a strong proud black Aboriginal woman that is here before you today to come and get help where I need it and fight for my rights.[23]

Throughout our inquiry, First Nations people with disability raised concerns about their interactions with police and corrections personnel, as well as conditions in adult prisons and youth detention centres. We heard about racist and ableist attitudes towards First Nations people with disability in these settings, as well as physical violence against them, and use of physical and chemical restraints.

Yorta Yorta and Barapa Barapa man Tyrone Justin lives with autism spectrum disorder, an acquired brain injury and ADHD. He has served four jail sentences.[24] He told us of racist and ableist experiences with corrections officers. While 'every now and again there is a good' prison officer, he said:

> there is only one to like five and that one gets casted out by the other screws. 'No, don't help him, he's black. Fuck him, he's a nuffy. Let him go. Just let him burn out he will get slotted anyway.' And this other screw goes like, 'What?' Like all the new prison officers go, 'That's not right.' Even their own kind pull them up and say that's not right, you can't do that. We see it all the time. Especially disabled.[25]

Another man described the humiliation of being strip searched by police, with whom he said he had violent interactions:

> I've had police try to snap my arm, smash my head into the ground … pretty much every time I've been arrested I've been injured in some way by the police.[26]

A First Nations woman with schizophrenia and bipolar disorder feels corrections staff treat her like she is a bad person, saying 'they're nasty' and 'swear at me to my face'.[27]

The need for proper administration of medication emerged as a recurrent theme. A number of First Nations people with disability said they were either over-medicated or medicated erratically while in custody.

During a private session, a 50-year-old First Nations man from Victoria with an acquired brain injury said he was given medication for his epilepsy while in prison. But, he said, he did not receive consistent treatment for his anxiety and depression with his medication being changed without him being told.[28]

An 18-year-old First Nations man with ADHD said he was prevented from accessing his ADHD medication while he was incarcerated. He said this resulted in a number of incidents due to his impulsive behaviour, including aggression towards guards.[29] While another First Nations man with psychosocial disability and post-traumatic stress disorder believed he was unnecessarily medicated. He said prison staff ‘tried to drug me up just to slow me down’.[30]

Inappropriate use of medication was a feature of Mr Justin’s evidence. He described the difficulties he faced in getting his medication in isolation and the effect missed medication had on him.[31] He told us of his experiences of isolation in custody. His longest period in isolation was 56 days with a break of seven hours after 28 days.[32]

Lengthy periods spent in isolation or solitary confinement also emerged as a theme in private sessions. One 25-year-old First Nations man who spent time in prison spoke of the two lengthy periods he said he spent in solitary confinement. He said the first period was for 10 weeks and the second for 80 days. He said this experience made him scared of confined spaces.[33] He described his experience in solitary confinement as ‘inhumane’. As a result, he said:

> I felt pretty low of myself, I felt like I couldn’t do it, because I suffer from depression, anxiety, a lot, so that just made me feel inhumane, like I was treated like an animal … I felt the whole time I was there, it was like they were trying to break my soul.[34]

A 28-year-old man described experiencing anxiety and panic attacks as a result of multiple experiences of solitary confinement and isolation. In his words, ‘they couldn’t be stuffed with you, they’d just leave you there’.[35]

We heard deeply troubling evidence about the treatment of two First Nations people, Melanie and ‘Winmartie’.[36] Melanie was held in her cell for 23 hours or more a day in a unit described by New South Wales Corrective Services clinical and forensic psychologists as ‘Dickensian’.[37] The Australian Human Rights Commission said it appeared Winmartie had been subject to ‘the most severe treatment while in prison, including frequent use of physical, mechanical and chemical restraints, seclusion and shackles when outside his cell’.[38]

We outline the experiences of Melanie, Winmartie and Mr Justin further in Volume 8, and make recommendations for reform to criminal justice systems.

6.4. Culture is healing

> When I was a kid and out in the community, doing things with my family and listening to my Nan's stories meant everything to me. Mostly I was connected to my culture through dancing, painting and going hunting. My uncle used to take us all out, my cousins and uncles and me, and we would go fishing and hunting and he would teach us about the land or he would teach us to paint and to dance. I had a lot of family where I grew up, so there was always a group of us doing these things together ...[39]

The importance of culture and its healing nature for First Nations people is undeniable. We were told this repeatedly by First Nations people with disability, including by those who had contact with criminal justice systems.

We learnt proper cultural support can help First Nations people with disability achieve better outcomes during and after engagement with criminal justice systems. We also heard about the importance of culture in reducing contact with the criminal justice system. We heard about the importance of having staff in prisons, juvenile detention centres and forensic units who are trained to work with First Nations people with complex needs.

Ms Cheryl Axleby has over 30 years' experience working within law and justice. Having worked with many First Nations people with disability she has an in-depth understanding of their experiences with criminal justice systems.[40] She said:

> Aboriginal and Torres Strait Islander culture also has a critical role to play in preventing crime and promoting rehabilitation and healing. Developing Aboriginal and Torres Strait Islander people's sense of identity and their connection to culture is a core component of holistic health and acts as a protective factor from keeping our people out of the justice system.[41]

We heard support for and access to culture can be patchy, or worse still, non-existent. We heard about the importance of Winmartie receiving culturally appropriate care and support. Winmartie's family made suggestions to the forensic disability unit about how to provide for Winmartie's cultural needs. We received evidence that the unit was responsive to these suggestions.[42] We were told the unit took the following measures to support First Nations people's cultural needs:

- having staff undertake basic cultural awareness training[43]
- employing an Aboriginal Liaison Officer[44]

- undertaking a cultural needs assessment for all forensic clients[45]
- embedding cultural competency in behaviour support plans[46]
- holding monthly meetings to discuss cultural aspects specific to clients.[47]

In Volume 8, we detail the experiences of Noongar man, 'Nathan', who lives with ADHD and comes from a disadvantaged background.[48] Describing his experiences at Banksia Hill Detention Centre in Western Australia, Nathan said there:

> was no acknowledgement of my culture at Banksia, even though there were Aboriginal officers there. We were always just seen as 'problem children'.[49]

Nathan's experience was echoed in private sessions. In one example, we heard from a 43-year-old woman that there was no respect for, or attention to, cultural practices where she is detained.[50]

Melanie's case is another example of inconsistent cultural support. Counsel Assisting submitted it is open to us to conclude Melanie was not adequately culturally supported at any time, either as a child or as an adult, while in the care and custody of the State of New South Wales.[51] We recognise the nuances of Melanie's experience. It is clear, however, that while she was in the care and custody of the State, Melanie experienced inconsistency in how her cultural identity and cultural needs were supported both as a child and an adult.[52]

Ms Megan Osborne, then the NSW Public Guardian told us about planning Melanie's transition from the forensic hospital to the community. Ms Obsorne said Melanie:

> made it quite clear to all of us that she is also wanting to connect back to her culture as well as a First Nations person, so work is underway as well to understand how we can achieve that.[53]

As we report in Volume 8, we were later advised Melanie had successfully transitioned out of the forensic hospital into appropriate accommodation in the community. Through Ms Osborne, Melanie told us 'I'm living in the community, I'm now free and living life to the fullest'.

We were told of Winmartie's deep connection to Country, family and culture. When far from Country, we were told he would become sick.[54] We heard of culturally appropriate supports that assist Winmartie, including:

- on-Country access visits with family[55]
- allowing ngangkaris (traditional healers) to work with him[56]
- allowing his cultural expression through his art.[57]

We heard about the value of organisations in building trust due to shared culture and community,[58] which enabled them to effectively facilitate prison visits by Elders,[59] psychosocial services,[60] support coordination,[61] and post-release support.[62] Ms Powney and Mr Barker gave evidence on behalf of Gallawah, an NDIS provider that provides services to many First Nations clients who are engaged with the criminal justice system.[63] They explained that their clients' complex conditions and layered disadvantage means their support needs in detention are complex and overlaid with a need for culturally safe support.[64]

First Nations-led organisations do valuable work supporting people to transition into the community. Some examples include connecting people with allied health and other support services while they are in prison so they are supported when they leave prison,[65] maintaining communication with family,[66] and creating post-release safety plans, which includes linking people with training, employment and accommodation services.[67]

Wulgunggo Ngalu Learning Place is a joint initiative between Corrections Victoria and the First Nations community.[68] It is a culturally appropriate learning place that supports up to 18 First Nations men who are undertaking community correction orders.[69] The voluntary program offers First Nations men the opportunity to learn new skills, reconnect with or strengthen culture, and participate in programs and activities to help them address their offending behaviour.[70]

Mr Justin told us of his experience at Wulgunggo Ngalu, where he had been for about three months on a community correction order.[71] He described Wulgunggo Ngalu as a very strong cultural place, which allows him to connect to his culture, identity and other First Nations men.[72] Mr Justin said he feels a lot safer, respected and understood at the centre, especially compared to his experiences in prison.[73] Describing Wulunggo Nglau as a 'healing centre', Mr Justin said 90 per cent of the men there feel the same as him on the importance of culture.[74] He explained:

> Culture is important because it's who you are. It's – being strong to your culture is strong to your identity. That's – I think that's a no-brainer. But culture is extremely important to know who you are and where you come from. Who your family is. Get more connected. Like, physically to the ground and spiritually to your people. Yes.[75]

It is critical First Nations people receive proper cultural support while in criminal justice settings. As we have observed, this can help First Nations people with disability achieve better outcomes during and after engagement with criminal justice systems. With this in mind, state and territory governments should review the effectiveness of their strategies directed to providing for, and ensuring the cultural safety of, First Nations people with disability in these settings.

Recommendation 9.3 Cultural safety of First Nations people in criminal justice settings

By the end of 2024, state and territory governments should review the effectiveness of their strategies, if any, directed to providing and ensuring the cultural safety of First Nations people with disability in criminal justice settings and in doing so take into consideration what the Royal Commission has heard about that issue.

The review findings and recommendations should be made public.

6.5. Culturally safe screening

We heard evidence about the limitations of existing screening and diagnostic tools for First Nations people with disability and the lack of culturally appropriate screening mechanisms. Inappropriate testing or a lack of assessment can cause misdiagnosis or a failure of diagnosis by failing to adequately account for First Nations people's cultural differences.[76] For instance, culturally biased testing may result in misdiagnosis because First Nations people's primary personality style is not one favoured or cultivated in the mainstream.[77]

We also heard about issues with screening and identification of disability while people are in the criminal justice system. This can lead to disadvantages throughout the court process,[78] lack of appropriate supports and involvement in the justice system.

Inadequate screening and identification practices, and a lack of culturally safe screening tools can affect access to services and treatment within justice systems. For example, Mr Thomas, whose experience we set out above, was not aware he had an intellectual disability until he was in his thirties.[79]

We heard that when First Nations people have underlying disabilities they can 'fall through the cracks' at an early stage.[80] Once they enter prison for example, a lack of appropriate screening can mean they do not receive appropriate supports, including NDIS supports.[81] Incorrect assessments can also affect key decisions through the criminal justice process. For instance, mental health assessments are often used in sentencing considerations, or to assess the risk of recidivism.[82]

Several witnesses spoke about the importance of culturally appropriate assessment tools to reduce the risk of misdiagnosis or false positive or false negative results.[83] For example, Ms Barney said audiological assessments in the Western medical system are not culturally safe for people who do not know they have hearing loss and why the test is being conducted. Additionally, they are unfamiliar with the testing devices used.[84] Ms Barney said a culturally safe assessment process should be inclusive and use visual and body language.[85]

Mr Lewis Shillito explained that in some cases, a First Nations person's interaction with the criminal justice system may be a trigger for diagnosis of their disability.[86] Receiving a first diagnosis within the justice system can result in a lack of follow-through support once a person leaves the system.[87]

Dr Marshall Watson cautioned that the use of screening tools alone is not sufficient to identify all issues relating to disability.[88] With developmental trauma affecting the majority of young First Nations people in custody, Dr Watson emphasised the importance of training staff at all levels within detention centres on this issue.[89] Clinicians with expertise in developmental trauma should lead the training alongside First Nations health professionals and community members to ensure that it is culturally safe.[90]

Dr Watson noted there are significant differences between jurisdictions in how young people are screened and how their needs are met in custody.[91] He said some staff hold negative assumptions about offenders, which can affect access to disability supports.[92] He has also witnessed staff deny people with disability access to assistance such as glasses, hearing aids and mobility aids.[93]

We received evidence about the Guddi Way Screen, a culturally safe assessment tool used to screen for cognitive impairment among First Nations people aged 16 and older.[94] The tool was developed by Synapse, the peak body for brain injury in Australia, in collaboration with First Nations communities and organisations in Far North Queensland.[95] Ms Jennifer Cullen, the CEO of Synapse, said by addressing a lack of culturally valid diagnostic tools, it reduced the power imbalance that exists when you apply a Western tool to a First Nations person with cognitive impairment.[96]

The Guddi Way Screen is underpinned by trauma-informed practice principles, and includes a culturally sensitive framework for engaging with First Nations communities.[97] It uses the 'yarning approach' to collect personal and health-related information and assess cognitive function.[98] It is an integral part of the cultural protocol developed in partnership with Elders and respected cultural advisors.[99]

As we explain in Volume 8, the Guddi Way Screen appears to be a promising practice that should be considered by corrective services agencies. In that volume we address the clear need to improve the cultural safety of current screening processes across Australia. The experiences outlined in this chapter inform the rationale for our recommendations in Volume 8, *Criminal justice and people with disability.*

Endnotes

1 Exhibit 11-33.1, 'Statement of Justen Thomas', 22 September 2020, at [11].
2 Susan Baidawi, Rubini Ball, Robyn Newitt, Lena Turnbull, Gayatri Kembhavi-Tam, Scott Avery, Rosemary Sheehan & Jade Purtell, *Care criminalisation of children with disability in child protection systems*, Report prepared for the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, May 2023, p 7.
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5 Transcript, 'IL', Public hearing 16, 17 September 2021, P-26 [22–23].
6 Exhibit 11-33.1, 'Statement of Justen Thomas', 22 September 2020, at [2], [6].
7 Exhibit 11-33.1, 'Statement of Justen Thomas', 22 September 2020, at [10].
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9 Exhibit 11-33.1, 'Statement of Justen Thomas', 22 September 2020, at [11].
10 Exhibit 11-33.1, 'Statement of Justen Thomas', 22 September 2020, at [12].
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12 Exhibit 11-1.3, NSW.0025.0001.0362; Exhibit 11-1.4, NSW.0024.0001.0166, p 1.
13 Transcript, 'Melanie', Public hearing 11, 16 February 2021, P-35 [39–42]; Exhibit 11-1.10, NSW.0024.0001.3702, pp 5–6.
14 Transcript, 'Melanie', Public hearing 11, 16 February 2021, P-36 [3-5].
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16 Exhibit 11-1.60, NSW.0035.0276.0001, pp 16–17, 20.
17 Exhibit 11-28.1, 'Statement of Geoffrey Thomas', 15 January 2021, at [24], [26], [38].
18 Exhibit 11-28.1, 'Statement of Geoffrey Thomas', 15 January 2021, at [39–48].
19 Exhibit 11-28.1, 'Statement of Geoffrey Thomas', 15 January 2021, at [8].
20 Exhibit 11-28.1, 'Statement of Geoffrey Thomas', 15 January 2021, at [6], [10–11].
21 Exhibit 11-28.1, 'Statement of Geoffrey Thomas', 15 January 2021, at [20].
22 Exhibit 27-77, 'Statement of Marshall Watson', 30 September 2022, at [40].
23 Transcript, 'Melanie', Public hearing 11, 16 February 2021, P-35 [39–42].
24 Transcript, Tyron Justin, Public hearing 27, 20 September 2022, P-98 [26–27].
25 Transcript, Tyron Justin, Public hearing 27, 20 September 2022, P-105 [26–33].
26 Name changed, private session, 'Rikki'.
27 Name changed, private session, 'Kehlani'.
28 Name changed, private session, 'Terence'.
29 Name changed, private session, 'Clive'.
30 Private session participant.
31 Transcript, Tyron Justin, Public hearing 27, 20 September 2022, P-102 [13–44].
32 Transcript, Tyron Justin, Public hearing 27, 20 September 2022, P-101 [1–19].
33 Private session participant.
34 Private session participant.
35 Name changed, private session, 'Rikki'.
36 Name changed to protect identity.
37 Exhibit 11-1.14, NSW.0022.0373.0001, p 3.
38 Exhibit 11-35.14, EXP.0049.0001.0171, p 43.
39 Exhibit 27-9, 'Statement of Nathan, 14 September 2022, at [4].
40 Exhibit 11-24.1, 'Statement of Cheryl Axleby', 5 February 2021, at [4].
41 Exhibit 11-24.1, 'Statement of Cheryl Axleby', 5 February 2021, at [88].
42 Exhibit 11-17.1, Written Statement of Tom Langcake, 20 January 2021, at [18].

43 Exhibit 11-17.1, ‘Statement of Tom Langcake’, 20 January 2021, at [20].
44 Exhibit 11-19.1, Supplementary Statement of Cecilia Gore, 16 March 2021, at [34].
45 Exhibit 11-19.1, Supplementary Statement of Cecilia Gore, 16 March 2021, at [34].
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49 Exhibit 27-9, ‘Statement of Nathan’, 14 September 2022, at [130].
50 Name changed, private session, ‘Kehlani’.
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52 Submission by the State of New South Wales in response to Counsel Assisting’s submissions in Public hearing 11, 26 April 2022, SUBM.0040.0001.0132, p 4.
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56 Transcript, Aunty Margret Campbell, Public hearing 11, 19 February 2021, P-269 [27]–P-271 [2].
57 Transcript, Aunty Margret Campbell, Public hearing 11, 19 February 2021, P-268 [12–13]; Transcript, Patrick McGee, Public hearing 11, 19 February 2021, P-308 [10–19].
58 Exhibit 27-76, Written Statement of Megan Krakouer, 16 September 2022, STAT.0630.0001.0001, [37–42].
59 Exhibit 27-24, Joint statement of Tina Powney and Trevor Barker, 9 September 2022, STAT.0595.0001.0001, [41].
60 Transcript, Megan Krakouer, Public hearing 27, 21 September 2022, P-193 [21–26]; Exhibit 27-76, ‘Written Statement of Megan Krakouer’, 16 September 2022, STAT.0630.0001.0001, [41–42].
61 Exhibit 27-24, ‘Joint statement of Tina Powney and Trevor Barker’, 9 September 2022, STAT.0595.0001.0001, at [41]; Transcript, Trevor Barker, Public hearing 27, 20 September 2022, P-76 [6–28].
62 Transcript, Megan Krakouer, Public hearing 27, 21 September 2022, P-201 [43–46], P-102 [1–14]; Exhibit 27-76, ‘Written Statement of Megan Krakouer’, 16 September 2022, at [42]; Exhibit 27-24, ‘Joint statement of Tina Powney and Trevor Barker’, 9 September 2022, at [37–38], [41].
63 Exhibit 27-24, ‘Joint statement of Tina Powney and Trevor Barker’, 9 September 2022, at [28].
64 Exhibit 27-24, ‘Joint statement of Tina Powney and Trevor Barker’, 9 September 2022, at [33-34].
65 Transcript, Trevor Barker, Public hearing 27, 20 September 2022, P-76 [1–17].
66 Transcript, Trevor Barker, Public hearing 27, 20 September 2022, P-76 [16–28].
67 Exhibit 27-76, ‘Written Statement of Megan Krakouer’, 16 September 2022, at [37].
68 Exhibit 27-24, ‘Joint statement of Tina Powney and Trevor Barker’, 9 September 2022, at [15].
69 Exhibit 27-24, ‘Joint statement of Tina Powney and Trevor Barker’, 9 September 2022, at [16].
70 Exhibit 27-24, ‘Joint statement of Tina Powney and Trevor Barker’, 9 September 2022, at [16].
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76 Exhibit 8-4.1, ‘Statement of Tracy Westerman’, 24 November 2020, [30]; Exhibit 27-77, ‘Statement of Dr Marshall Watson’, 30 September 2022, [31].
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79 Exhibit 11-33.1, ‘Statement of Justen Thomas’, 22 September 2020, at [3].
80 Exhibit 11-23.1, ‘Statement of Lewis Shillito’, 12 January 2021, at [39].
81 Exhibit 11-24.1, ‘Statement of Cheryl Axleby’, 5 February 2021, at [57]; Exhibit 27-24, ‘Joint statement of Tina Powney and Trevor Barker’, 9 September 2022, at [45].
82 Exhibit 8-4.1, ‘Statement of Tracy Westerman’, 24 November 2020, at [39].

83 Transcript, Cheryl Axleby, Public hearing 11, 23 February 2021, P-453 [36–38]; Exhibit 27-77, ‘Statement of Dr Marshall Watson’, 30 September 2022, at [31–32].
84 Transcript, Jody Barney, Public hearing 27, 21 September 2022, P-162 [15–26].
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86 Transcript, Lewis Shillito, Public hearing 11, 23 February 2021, P-463 [16-18].
87 Transcript, Cheryl Axleby, Public hearing 11, 23 February 2021, P-464 [29-35].
88 Exhibit 27-77, ‘Statement of Dr Marshall Watson’, 30 September 2022, at [32].
89 Exhibit 27-77, ‘Statement of Dr Marshall Watson’, 30 September 2022, at [40], [48–49].
90 Exhibit 27-77, ‘Statement of Dr Marshall Watson’, 30 September 2022, at [50].
91 Exhibit 27-77, ‘Statement of Dr Marshall Watson’, 30 September 2022, at [42].
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94 Exhibit 27-29, Joint statement of Jennifer Cullen and Adam Schickerling, 9 September 2022, at [23].
95 Transcript, Jennifer Cullen, Public hearing 27, 20 September 2022, P-135 [28–30].
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98 Exhibit 27-29, ‘Joint statement of Jennifer Cullen and Adam Schickerling’, 9 September 2022, at [35–36].
99 Exhibit 27-29, ‘Joint statement of Jennifer Cullen and Adam Schickerling’, 9 September 2022, at [32].

7. The unmet potential of the NDIS for First Nations people with disability

Key points

- First Nations people with disability experience significant barriers accessing and using the National Disability Insurance Scheme (NDIS), which are exacerbated in remote and very remote communities. This constitutes systemic neglect.
- The issue of service delivery in remote communities is not new. Challenges in delivering services in remote communities include high costs of service delivery, low number of participants, housing shortages, and the absence of local workforces. In many communities, the gap between the needs of participants and services available creates a ‘thin market’.
- Other barriers to First Nations people with disability accessing the NDIS include:
    - inherent tensions between holistic ‘family-centred’ service delivery and the transactional approach of the NDIS, which focuses on individual plans and goals
    - the complexity of the NDIS
    - a lack of knowledge and understanding of the NDIS within First Nations communities
    - a lack of local National Disability Insurance Agency (NDIA) presence
    - a lack of cultural safety.
- A market-based approach is insufficient to overcome structural barriers to the NDIS in remote communities. Place-based solutions that work with participants are needed. This requires long-term investment and flexible funding to build capacity of local workforces and Aboriginal Community Controlled Organisations and Aboriginal Community Controlled Health Organisations.
- Participation in cultural life is equally essential for First Nations people with disability as social and economic participation, and this should be recognised in the context of the NDIS.
- In the absence of appropriate disability services, First Nations family members often care for those with disability. Without adequate support and capacity-building, they are vulnerable to carers’ burnout. The NDIA should clarify funding and supports available to family members.

7.1. Introduction

First Nations people with disability and stakeholders explained the challenges they experienced accessing and using the National Disability Insurance Scheme (NDIS). They identified barriers to obtaining the evidence to apply for the NDIS, the complexity of navigating the scheme, and the difficulty in accessing appropriate and quality services.

This chapter examines concerns regarding the operation of the NDIS by First Nations people with disability and, in particular, the matters raised at Public hearing 25, ‘The operation of the NDIS for First Nations people with disability in remote and very remote communities’.

7.2. The operation of the NDIS in remote and very remote communities

Public hearing 25 examined the key barriers First Nations people with disability experience living in remote and very remote communities when accessing disability supports and services through the NDIS. The hearing explored whether and how deficiencies in the operation of the NDIS in these communities contribute to violence against, and abuse, neglect and exploitation of, First Nations people with disability. The hearing examined whether the NDIS model was structurally fit for purpose and capable of delivering its objectives in remote communities.

According to National Disability Insurance Agency (NDIA) data as at 31 December 2022, approximately 10 per cent of First Nations NDIS participants (4,350 people) lived in remote and very remote areas.[1] As at 31 March 2022, 1.5 per cent of NDIS participants (8,007 people) across the country lived in remote or very remote areas, approximately half of whom are First Nations people.[2]

We also heard that NDIS plans are often underused in remote areas, and that community-controlled organisations fill the gaps in service provision, often without recompense and, at times, without necessary expertise.[3]

Delivering disability services in remote communities

Many witnesses at Public hearing 25 said that they struggled to, or could not, access the supports and services they needed due to those services being unavailable or very limited, despite having funding in their NDIS plans. In some instances, witnesses felt that they were worse off under the NDIS than they were under state and territory disability support schemes.[4]

Service delivery in remote communities was a challenge before the existence of the NDIS. In many remote communities, disability services were primarily delivered through block funding arrangements, or direct contracts between state and territory governments and a service provider.[5] In 2011, prior to the NDIS rollout, the Productivity Commission reported that support services in remote communities were either non-existent or limited to basic care and allied health programs.[6] The Productivity Commission found it was highly unlikely any disability services would exist in remote communities without block funding (at least in the short and medium terms) due to:[7]

- the absence of a competitive market for disability services
- the social pressures that may be applied to people with disability who manage their own funds.

What we heard about the lack of services

Consistent with the predictions made by the Productivity Commission, witnesses at Public hearing 25 told us that disability services were virtually non-existent in their communities. They described the difficulties they had in accessing supports, particularly:

- locally based support workers[8]
- allied health services[9]
- support coordinators,[10] particularly specialised support coordinators[11]
- respite services[12]
- Supported Independent Living (SIL) services and specialist disability accommodation (SDA)[13]
- assistive technology[14]
- accessible transport.[15]

Several witnesses also identified a lack of specialist services to provide the assessments and diagnoses required to access the NDIS.[16]

Paulette, a woman with Machado-Joseph disease who lives in Gunbalanya, said, 'I don't think there are any support workers in my community. No one else apart from my family helps me with things.'[17] Jazsikah, a Yawuru and Nimanburu woman living in Fitzroy Crossing, gave evidence about navigating the NDIS for her two young sons.[18] She said, 'there's no services whatsoever' for them or other children with disability.[19] She said she did not feel the NDIA properly understood what life is like in the Kimberley – in particular, the high prices, seasonal flooding and long distances people need to travel to access services.[20]

Ms Emily Carter, a Gooniyandi-Kija woman and CEO of Marninwarntikura Women's Resource Centre (MWRC), and Dr Lauren Rice, Research Fellow at the University of Sydney, gave evidence about First Nations people's experiences with the NDIS in the Fitzroy Valley.[21] They said:

> The lack of disability services, such as day programs and support workers, means that some people with disability are unable to leave their often-overcrowded houses. They have no option but to sit in their homes in 40+ degree heat because they cannot afford aircon 24/7. Without services and supports, people who use wheelchairs, for example, cannot participate in community activities, such as accessing the river or going camping, which are important for their cultural enrichment.[22]

‘Daisy’, a Warumungu woman from Tennant Creek, described the lack of disability services and infrastructure available in Tennant Creek and how this has affected her life and that of her son ‘Joziah’.[23] Daisy has diabetes, which led to one of her legs being amputated in 2015.[24] Joziah has spastic quadriplegia, cerebral palsy, dysphasia and cognitive impairment.[25] He moved to Alice Springs in 2020 and is now receiving supports that he would not have been able to receive if he had remained in Tennant Creek.[26] Daisy said there was ‘nothing for him’ in Tennant Creek.[27] However, her family misses Joziah, and she wishes he could visit more.[28] She said there are important cultural activities that Joziah needs to come back for.[29]

Mrs Kunmanara (Margaret) Smith, the Deputy Chairperson of NPY Women’s Council (NPYWC), and Ms Kim McRae, Tjungu Aged and Disability Service team leader, gave evidence about the experiences of A<u>n</u>angu on the Ngaanyatjarra Pitjantjatjara Yankunytjatjara (NPY) Lands. The NPY Lands consist of 25 very remote communities and homelands spread across 350,000 square kilometres of semi-arid country.[30] To put the size of this area into perspective, the combined size of Victoria and Tasmania is 295,845 square kilometres.[31] For the A<u>n</u>angu people, lore and culture is very strong.[32] Mrs Smith and Ms McRae said that while some new service providers had been established in their community since the NDIS began, they often lacked cultural competency and sufficient knowledge of life in remote communities.[33]

We heard that while drive-in-drive-out and fly-in-fly-out providers visit some remote communities, they tend to be infrequent and accessing their services involves lengthy wait periods.[34] Witnesses told us they value and trust face-to-face and locally based services that understand the realities of life in a remote community.[35]

We heard similar stories in our community engagements on the Torres Strait Islands.[36] Due to the cost of travel, providers see as many clients as they can when they visit, but limit the time they spend with each person.[37] This leaves participants feeling they are not receiving comprehensive assessments or adequate treatment.[38]

Another concern raised was the high cost of services. In one instance, we heard that respite for one week could cost between $8,000 and $16,000, depending on the needs of the participant.[39] A nurse in the Northern Territory described the NDIS as ‘a licence to print money’.[40] She felt that there were a lot of people making a lot of money from the NDIS, but that people with disability still did not receive quality services.[41]

The NDIS model relies on a healthy marketplace ‘where participants can use their NDIS plans to purchase the supports and services that best meet their needs’.[42] Ms Kitsa Papadopoulos, the NDIA’s Branch Manager, Market Intervention and Commissioning, acknowledged there is a gap between the needs of participants and the services available in remote and very remote communities,[43] where there are ‘thin markets’.[44]

Delays in receiving equipment

> I still don't know whether there is NDIS money to fix my scooter. I wonder why I can't get a new scooter, rather than fixing my broken one, which is old and doesn't work properly.[45]

First Nations witnesses in remote communities described major delays in receiving equipment and issues with timely repairs.[46] For example, Ronita, a First Nations woman with disability living in Fitzroy Crossing, told us about delays in receiving repairs to her wheelchair. Ronita said she has been waiting 'years' for a new wheelchair and hoists to help her in her home.[47] Without her wheelchair, Ronita is not able to move around independently.[48] She described waiting for her equipment as 'stressful'.[49] Her mother, Topsy, said Ronita's wheelchair has been 'in a state of complete disrepair for years'.[50] Topsy told us that on one occasion, she was required to go to the town's local tip to find parts to repair the wheelchair herself.[51]

NDIA representative Scott McNaughton, General Manager, National Delivery, conceded that the wait times the witnesses reported for supplying equipment 'are simply not good enough'.[52] He said they were contrary to the NDIA's service guarantees and internal performance indicators, which specify equipment be delivered within 60 or 90 days from being identified in someone's plan.[53]

Impact of the lack of services

> I have the funding but it is unable to be delivered in my community so I live in Cairns which is an 8 hour drive home by 4 wheel drive to my community – I have not been home since 2016 and am suffering by not being in my community.[54]

A lack of services not only limits the choice and control of First Nations people with disability in remote communities, but may mean they are more reliant on family members and First Nations Community Controlled Organisations to provide disability services. Where this is not possible, they are required to move off Country.

Witnesses told us about their deep connection with Country and culture. Many said having to move off Country to receive services has a significant impact on their wellbeing and that of their families.[55] Mudge Bedford, a Bunuba man from Fitzroy Crossing, described the special connection his son Bubbaboy has with water, especially the Martuwarra River.[56]

> … [Bubbaboy] also loves being outdoors and being in the river, especially in the water he don't – he loves that water. I don't know if that water – him and the water has their own special connection. He won't leave the water. The water won't leave him. Yeah, he – he loves to be out on Country and most of the time that's the only way I can get him off his iPad.[57]

Similarly, when asked whether living on Country was important for her sons' health and wellbeing, Jazsikah explained:[58]

> Yes, because they were raised here; okay, so they've had that automatic connection anyway. They … know when it's cold weather. They know the plants, the water … the dirt … it's like an unseen connection that you just can't really explain unless you actually sit and you pay attention to how they respond to the changes, … the seasonal changes or to the changes in anything – that's just so norm to them.[59]

Her boys have a deep and important connection to Country, and when on Country they engage in cultural activities and communicate in language.[60]

The situation is complex for parents of children with disability. Many parents feel they are doing their child a disservice by staying in a place where there are no disability services, yet moving means they are forced to leave Country, culture, language and kinship.[61]

Mrs Smith and Ms McRae said that for Anangu with disability to live a good life, they want to live in their communities on the NPY Lands with family. For many, this desire takes precedence over their disability needs and the quality of care they receive:[62]

> It hurts our community when people have to move off Country. Anangu need family around them, they cannot live on their own. It is heartbreaking when the old people move away and cannot come home for funerals or to pass on cultural knowledge, or when the young people are not there to receive it.[63]

The Northern Territory Public Guardian and Trustee, Ms Beth Walker, told us that when a First Nations participant is forced to move away from Country and kin, 'engagement in their new environment and services might be sub-optimal, and behavioural and mental health issues may worsen, or develop as a consequence'. [64] She noted her office had observed funding for return to Country trips in participants plans are increasingly being denied or reduced.[65] She suggested the absence of, or reduction in, NDIS funding for participants to return to Country can cause 'even greater disengagement with services and worsening behavioural issues'.[66]

Barriers to accessing the NDIS

Obtaining diagnoses

> The lack of specialist services on the NPY Lands creates a barrier for children with disabilities to obtain an official diagnosis. This means there are many Aṉangu children who are unable to access supports at school and the NDIS, and miss out on receiving essential services and supports.[67]

Witnesses spoke about difficulties applying to the NDIS and obtaining evidence to support applications. Ms Riemer, deputy CEO of First Peoples Disability Network (FPDN), explained that diagnostic tools that label an individual do not translate culturally or into language.[68]

Ms McRae explained that Aṉangu families are sometimes reluctant to undergo assessments because they feel shame that people might blame them for their child having a disability.[69] We discuss the challenge and risk of diagnosis for First Nations people with disability in Chapter 2.

Access to culturally appropriate assessments is problematic in remote communities. There is a lack of assessment practitioners in remote areas like the NPY Lands and Fitzroy Valley.[70] This means First Nations people with disability may be unable to undergo assessments, or have no choice but to seek assessments from unfamiliar practitioners who might provide culturally unsafe care.[71]

Although Public hearing 25 did not examine the barriers to obtaining assessments and diagnosis in detail, we accept Counsel Assisting’s submission that the NDIA should:[72]

- examine the availability of culturally appropriate assessments
- consider forming partnerships with First Nations disability and health organisations to improve the availability of culturally appropriate assessments
- consider how the NDIS eligibility criteria may need to be modified in circumstances where First Nations people have difficulties accessing culturally safe and appropriate assessments or lack sufficient documentation.

Complexity

… there are still people out there who feel they don't understand what the NDIA is and will avoid at all costs because they – they feel uncomfortable, they don't know what's going to happen, they are suspicious about how that might impact on them and just don't engage.[73]

The complexity of the NDIS has impeded First Nations people's access to the scheme and to disability supports in remote communities. Many witnesses had a limited understanding of the NDIS and how it could help them.

Mrs Bakoi Namok, a Torres Strait Islander woman, described the challenges she and her family experienced navigating the NDIS after her son had a stroke in late 2021.[74] She said the NDIA did not offer interpreters during meetings, so she had to rely on her daughter Kernisha (Nisha) or son Bernard to translate.[75] She said:

> I didn't really understand what was happening, I felt a bit rushed and that things weren't explained properly to us. Nisha and I are still trying to understand what the NDIS is all about.[76]

Mrs Namok said she thought that there was an NDIS office on Thursday Island where she lived, but she did not know where it was.[77]

At the time of Public hearing 25, the NDIS had been operating in Tennant Creek for approximately eight years. [78] Witnesses from Tennant Creek still had limited understanding about their NDIS plans, how much funding they have, and what that funding can be used for.[79] Emily Sherwood, a First Nations woman who has reduced mobility and speech, told us: 'I find the whole process very confusing. I don't feel empowered or in control of how my package is spent.'[80]

Witnesses described the language in NDIS plans as technical, bureaucratic and unclear – even the plain English version was difficult to understand.[81] They told us that concepts that underpin the NDIS, such as it being an 'insurance scheme' and the setting of goals, were 'foreign' and not culturally relevant.[82]

The cultural, language and literacy barriers amongst First Nations NDIS participants in remote communities limit the ability of those participants to exercise choice and control.[83] We heard that much of the information distributed by the NDIS was culturally inappropriate and incomprehensible.[84] Simplifying educational material, as well as improving the cultural competency of NDIA staff and increasing access to interpreters, would address many of these barriers.[85]

Many witnesses described difficulties understanding concepts or the consequences of signing forms, and expressed confusion about the quantity and purpose of funding in their plans.[86] A particular concern raised by ACCOs during community engagements was that participants are not aware of their rights and entitlements under the NDIS, and frequently sign forms they do not understand or which have not been properly explained to them.[87]

Community connector programs

The NDIA runs three community connector programs to support people with disability in remote communities to access and navigate the NDIS. This includes the Remote Community Connector (RCC); Evidence, Access and Coordination of Planning (EACP); and Remote Early Childhood Services (RECS) programs.[88]

The RCC program commenced in 2017 and aims to promote awareness of the NDIS, support people to connect with mainstream services, help people access the NDIS and provide support with planning and implementing supports.[89] As at 29 July 2022, there were 209 RCCs servicing approximately 300 (27 per cent) of 1,100 remote and very remote communities across all states and territories except Victoria, Tasmania and the Australian Capital Territory.[90] RCCs must be of Aboriginal and/or Torres Strait Islander descent and have a detailed understanding of the communities they are working in.[91]

The EACP program currently employs 20 staff covering over 150 communities in Western Australia, the Northern Territory and South Australia to assist people in gathering the evidence required to access the NDIS.[92] The RECS program currently operates in the Kimberley in Western Australia, and supports children younger than seven years old with developmental delay or disability to access supports.[93]

Witnesses at Public hearing 25 described mixed experiences of the community connector programs. Several ACCHOs spoke about the Kimberley Supports Consortium, which was developed in 2019 and comprises member ACCOs who deliver the community connector programs.[94] Under this model, the Kimberly Aboriginal Medical Service (KAMS) is the contract holder and distributes funds to consortium members to deliver the programs.[95] As at 17 June 2022, there were six full-time equivalent RCCs and five EACP staff employed through the Kimberley Consortium.[96] Ms Cassie Atchison, CEO of Broome Regional Aboriginal Medical Service (BRAMS), described the RCCs as ‘extremely powerful’ because they engaged with community members who were not previously aware they were eligible for the NDIS and are now linked with services.[97] Ms Jenny Bedford, Chief Operating Officer of KAMs, said in the last two years the RCC program had supported 597 people, and the EACP program had enabled 309 people to access services in the Kimberley.[98]

However, Ms Carter and Dr Rice explained that ACCOs in the Fitzroy Valley declined RCC funding in 2020 because they did not have the resources and training to deliver the program.[99] Similarly, Ms Smith and Ms McRae said NPYWC surrendered the RCC funding because there was a lack of training for RCC staff and they did not like the way the NDIA expected RCCs to engage with community.[100] Despite this, NPYWC have tried to continue to work with the program.[101]

Mrs Smith and Ms McRae outlined ongoing issues with the lack of appropriate training of the RCCs.[102] They also said there had been a failure to manage the complexity of relationships that RCCs may have with some participants, including instances where RCCs may be required to avoid speaking to, or interacting with, certain community members due to cultural protocols.[103] They said the NDIA 'injecting money into the RCC program is not meeting its commitment to engage in a culturally safe manner with remote First Nations communities'.[104]

The evidence presented at the hearing indicated that the following factors are important for the community connector programs to work well:

- adequate infrastructure within a community, including established ACCOs and ACCHOs with the frameworks, interest and capacity to deliver the programs[105]
- adequate investment in the programs and the ACCOs that deliver them, including long-term funding[106]
- quality training for staff employed through the RCC, EACP and RECS programs[107]
- local First Nations leadership and delivery, with necessary support and funding.[108]

The Australian Government accepted Counsel Assisting's submission that it should consider further expansion of the RCC program.[109] The NDIA is working with existing service partners to expand their footprint, where practical, and has commenced negotiations with several ACCOs not currently engaged in the current RCC program.[110] The NDIA said they should continue to oversee implementation of the community connectors programs, and that changes to program design will be done in consultation with the community.[111]

The NDIA recognised that longer term contracts better support remote programs.[112] It stated it has structured recent contracts for more than two years, with further options to extend where a program will continue to deliver in its existing capacity, subject to available budget.[113]

Recommendation 9.4 Expand community connector programs

The National Disability Insurance Agency should increase the number and coverage of the community connector programs for First Nations people with disability in remote areas. The implementation of the programs should be community-led and delivered. This expansion must be accompanied by adequate long-term funding for the programs and organisations delivering the programs, with sufficient training for staff delivering the programs.

In regions where English is not the preferred language for First Nations people, the programs should focus on recruiting staff who speak local languages.

The need for flexibility

To help the individual, you often have to support and build the capacity of the family and community.[114]

There is an inherent tension between the preference of many First Nations communities for a holistic, 'family-centred' approach to service delivery and the NDIS model, which has a more transactional approach focusing on individual plans and goals.

Mrs Smith and Ms McRae explained how a family-centred approach acknowledges the role of family both at the core of First Nations identity and as key to delivering support:[115]

> A narrow focus on the individual, without an understanding of the importance of family and community, conflicts with the Anangu way of living … To help the individual, you often have to support and build the capacity of the family and community … If the NDIS continues to operate without any flexibility to work with families, the scheme will limit individual choice and control for Anangu.[116]

Ms McRae said while the NDIS has led to more money being provided through participants' plans, people cannot necessarily use that money in the way they would like to.[117] For example, they cannot use their funds to buy practical things like food, swags and blankets.[118] Mrs Smith and Ms McRae emphasised that participants cannot seek out disability supports when their basic needs are not being met.[119]

> In our view, the NDIS is designed with an inherent assumption built in that all people with a disability start from a baseline where their basic needs are met each day. That everyone has a moderate level of literacy and access to food and shelter, and that a wide range of services are available to all. On the NPY Lands, these assumptions are false. For Anangu, the need for basic resources (food, bedding and basic goods) are not always satisfied and must be satisfied first. Only then can people consider the more complex and less immediate needs that result from their disability or the disability of someone they are caring for.[120]

Ms McRae said some participants feel there were better services before the NDIS was introduced, because the NPYWC were able to be much more family-centred.[121]

For example, a number of children missed out on therapies because they were always away from the community whenever the therapist came to visit. She said that due to the complexities of life out in the communities, sometimes the only way to ensure participants received the services and treatment they needed was to bring them into town for 'blocks of therapy'.[122] This is beneficial because their families 'are not distracted by what is going on in the community'.[123]

Ms McRae said that while the NDIS will cover the cost of therapies during these visits, it will not cover accommodation for the participant or their family.[124] On one occasion when she sought funding for accommodation, an NDIA staff member said to her 'the NDIS does not fund family holidays', which 'missed the point completely'.[125]

The evidence from NPYWC demonstrates that the current NDIA individualised funding model is characterised by inflexibility. This can limit individual participant's choice, control and ability to access reasonable and necessary supports. There is no flexibility within the scheme to accommodate the local solutions put forward by NPYWC, including bringing participants and their families into town for therapy, even though this would reduce wastage of NDIS funds.

During Public hearing 25, the NDIA representative, Mr Scott McNaughton, accepted:

> there is a need for more flexibility. There is a need to make the scheme easy to understand and the need to make the scheme more community-led.[126]

Mr McNaughton pointed to the way KAMS and BRAMS work with the community through the Kimberley Consortium, as a 'great flagship' in how this can be achieved.[127]

The submissions made by the Australian Government after Public hearing 25 accepted that further work is required 'to make the design and operation of the NDIS more flexible to better support First Nations people with disability in remote communities'.[128] The submission observed 'while some communities may have a positive experience with the NDIS, its operation necessarily requires flexibility and, in many cases, tailoring to specific needs'.[129]

The submissions recorded several initiatives designed to improve the NDIS to suit the needs of First Nations people with disability, including:[130]

- a dedicated access pathway for remote First Nations participants
- NDIA remote planners
- the NDIA's Community Connector Program (described above).

The Australian Government submitted that outcomes are improving for First Nations participants. It pointed to the increase in 'plan utilisation rates' by First Nations participants living in remote and very remote areas from 57 per cent at 30 September 2021 to 60 per cent at 30 September 2022.[131] 'Plan utilisation' refers to the amount of funds used by a participant from their NDIS package.

We acknowledge that greater access to the scheme by First Nations people with disability and increased plan utilisation by NDIS participants are positive indications. However, they do not necessarily demonstrate improved outcomes for First Nations participants, including culturally safe, quality supports and services.

Challenges to delivering services in remote communities

> [I]t takes me 12 hours to drive from Cairns to Aurukun (with breaks). We have a reading of around 2,200km on the odometer by the end of these trips. Cairns is Aurukun's nearest regional city. It becomes clearer why service providers are reluctant to deliver services to remote communities and why the costs to deliver these services are so high once you have travelled these distances.[132]

There are substantial challenges associated with delivering services in remote communities. These create risks to ongoing service provision by existing providers, and barriers to market entry for new providers.[133] According to a report by the NDIA, service providers identified the following challenges in remote communities:[134]

- a low number of participants
- uncertain demand
- high costs of service delivery
- inadequate pricing models
- the logistical challenges of travelling to remote communities, including long distances, employee safety and limited accommodation options.

We heard instances where the NDIS Pricing Arrangements and Price Limits were not sufficient to provide for the high costs associated with service delivery in remote communities.[135] Service providers described operating 'in a deficit' to provide face-to-face NDIS services.[136] The complexity of the registration process, costs of administration and overheads create barriers to establishing new First Nations service providers.[137]

Ms Turner AM, CEO of NACCHO, said the cultural competence and safety of mainstream NDIS providers was 'very minimal'.[138] She warned that an absence of cultural safety creates risks that First Nations people will disengage from the NDIS, as well as creating barriers to using plans and receiving supports.[139] We heard the limited availability of culturally safe NDIS services compounds the issue of thin markets.[140]

The witnesses representing First Nations Community Controlled Organisations described the reputational risks to their organisation when promoting the NDIS to community, or supporting people to apply to the NDIS.[141] They outlined that when promised services are not delivered or do not meet expectations, it can erode the community's trust in the NDIA and in the ACCOs or ACCHOs themselves.[142] Ms Carter and Ms Rice described the significant unfunded burden placed on ACCOs to fill the gap created when the NDIS has not delivered adequate services for people with disability.[143]

National Disability Services proposed that increasing knowledge of the NDIS meant 'meeting the community where they are', through greater connection between Local Area Coordinators and community-controlled organisations.[144]

Ms Turner AM outlined that a for-profit system is at odds with the not-for-profit model that underlies the community-controlled sector.[145] She said that to accommodate the shift required ACCOs and ACCHOs to invest in new infrastructure, human resources, marketing and other areas.[146]

NDIA action to address thin markets

The Royal Commission heard evidence that despite the clear findings of the Productivity Commission in 2011, very little, if any, meaningful action was taken to address the barriers to delivering services in remote communities during the NDIS rollout.[147] According to Mr McNaughton, the focus for the NDIA during this period was 'getting people access to the scheme'.[148]

In December 2019, the Disability Reform Council agreed to 'a more flexible approach to address market challenges … recognising a "one-size-fits-all" approach to delivering the NDIS is not suitable to address market gaps faced by certain geographic locations, particular cohorts or disability support types'.[149] This led to the thin market projects, which is an ongoing initiative led by the NDIA, the Department of Social Services (DSS), and state and territory governments.[150]

The NDIA has developed three 'interventions' to address market challenges: market facilitation, coordinated funding proposals and direct commissioning.[151]

During Public hearing 25, Ms Papadopoulos, NDIA Branch Manager for Market Intervention and Commissioning, said the NDIA determines which approach and intervention is most appropriate for each community, and that there is 'a lot of flexibility' in their approach.[152]

An evaluation of the thin market projects concluded the interventions have had mixed outcomes.[153] There is limited evidence of their effectiveness in addressing the significant barriers to accessing and utilising the NDIS in remote communities.[154] The mixed outcome of these trials reinforces the need for locally based solutions and a reduced reliance on market-based models in regions where this is ineffective or impractical.

In addition to the thin market projects, the NDIA commenced the Ngukurr project in 2020.[155] This took a whole-of-community approach to addressing barriers to accessing and using the NDIS in Ngukurr, a very remote First Nations community in southeast Arnhem Land in the Northern Territory.[156] After a community visit by NDIA representatives, the NDIA confirmed 'the traditional mainstream model is not and will not work at Ngukurr or in other remote areas'.[157] Mr McNaughton said the NDIA accepted this conclusion, agreeing that 'we need to do more to design some of our policies and practice that are more tailored and fit for purpose for remote communities'.[158]

The adequacy of the NDIA's response

> My observation is that the NDIS really needs to be looked at and the NDIA need to think deeply about how the scheme can actually assist Aboriginal people with disability in remote communities. […] Something has to change so that people with a disability in remote communities are being properly supported.[159]

The evidence from First Nations people with disability and their families, and from First Nations Community Controlled Organisations was powerful and consistent. It demonstrates that participants in remote areas do not have consistent access to quality and culturally safe disability services and supports.

Issues of service delivery in remote communities are not new. They were set out by the Productivity Commission prior to the rollout of the NDIS.[160] We accept that the Australian Government has taken steps to address the issue of thin markets.[161] However, despite approximately four years of market interventions, the NDIA's own evaluation found that the potential of these initiatives is uncertain.[162] This suggests the Australian Government is no closer to resolving the issue of thin markets in remote communities.

The Australian Government accepted Counsel Assisting's submission that a purely market-based approach is insufficient to overcome the structural barriers that impact First Nations people's access to, and utilisation of, the NDIS in remote communities.[163] It furthermore accepted that, where market-based interventions are insufficient to address market challenges, 'more direct interventions may be required, such as through direct commissioning or integration with other government services'.[164] The Australian Government noted this 'should be balanced to ensure choice and control and maintain the intent of the NDIS design'.[165]

It is clear a great deal more needs to be done to ensure First Nations people with disability in remote communities receive quality and safe disability supports. The evidence justifies a finding that First Nations people with disability have been and continue to be subject to systemic neglect by the NDIS. To halt the ongoing systemic neglect of First Nations people with disability in remote communities, a whole-of-government approach, with clearly defined strategies and outcomes, is urgently required.

During Public hearing 25, the Chair of this Royal Commission asked Mr McNaughton whether the NDIA was trying, through the market interventions, to 'adapt a program, a structure, a scheme that really isn't capable of being reformed in the way that is required to address the needs of First Nations people with disability in remote areas'.[166] Mr McNaughton expressed the view the NDIS could operate effectively within the existing legislative framework, in particular with the greater flexibility that recent amendments to the legislation allow.[167]

This view was echoed by witnesses who felt that with significant reform, the NDIS could meet the needs of First Nations people with disability in remote communities. We discuss options for such reforms further below.

7.3. A community-based approach and alternative funding models

During Public hearing 25, Commissioner Mason put the proposition to the NDIA representative that 'community development' was missing from the way it responded to issues in remote communities.[168] She pointed out that the NDIA's language and approach in remote communities is about market supply and demand, which is inconsistent with the ground-up community development approach of the First Nations community-controlled sector.[169]

Ms Riemer, Deputy CEO of FPDN, and Mr Griffis, CEO of FPDN, said there needed to be greater education and training in a 'whole of community approach'.[170] This involves going into communities and mapping local skill sets and areas of development.[171] Ms Riemer explained this assessment could involve asking the following questions:

> What is already in the community, what can be developed, what are the skill sets already there? How can further skill sets be developed? What needs to be done to sustain that community for individuals to stay and live on Country and be backed by, you know, appropriate block funding or other funding mechanisms to support people to stay on Country.[172]

Ms Papadopoulos acknowledged the NDIA is 'learning' and is beginning to have conversations about community development and a whole-of-community approach.[173] Mr McNaughton similarly recognised the importance of community-led solutions.[174]

In response to Counsel Assisting submissions, the Australian Government acknowledged the importance of investing in local First Nations organisations and workforces in remote and very remote communities.[175] It also acknowledged the need for place-based solutions in remote service delivery, working closely with participants to access, engage or commission the supports needed.[176]

Ultimately, a ground-up approach requires long-term investment and a flexible approach to funding in remote communities. This is required to build the local workforce and build the capacity of First Nations Community Controlled Organisations to fill the gaps in the market.

Block funding

The term 'block funding' is often associated with the dominant funding model for disability services that existed prior to the NDIS. Under this model, governments funded service providers directly.[177] Block funding arrangements are still used by the NDIA and DSS, and involve the provision of specific supports to NDIS participants through a contract between the government and a service provider. They are often characterised as delivering a specific outcome under the *National Disability Insurance Scheme Act 2013* (Cth) (*NDIS Act*), and are in place to provide supports not included in a participant's plan.[178] Volume 5, *Governing for inclusion*, discusses the background to the NDIS, including the objects and principles of the *NDIS Act* and the move from block-funded services to individualised funding.

Block funding does not replace individualised funding but wraps around 'to complement and support the operation of the NDIS'.[179] It has been applied to various programs and trials in remote communities in an attempt to improve First Nations peoples' participation in and access to the NDIS.

In Public hearing 25, the NDIA informed us that the budget to provide supports to remote areas had been extended to $14 million in block funding.[180] It also told us that block-funded programs over the 2021–22 financial year comprised $30.6 million, accounting for approximately 0.1 per cent of the NDIA's total expenditure.[181] NDIA block-funded programs include the RCC, EACP and RECS programs.[182]

In early 2022, the *National Disability Insurance Scheme Amendment (Participant Service Guarantee and Other Measures) Act 2022* (Cth) was passed. This legislation made a number of changes to the *NDIS Act,* including to section 14. New provisions specifying the purposes for which the NDIA may provide funding to persons or entities were inserted into subsection (1). The Explanatory Memorandum that accompanied the amendments outlines that this amendment was a response to recommendations in an Independent Review of the *NDIS Act*,[183] and creates a 'new set of purposes for which the NDIA may provide funding to build the capacity of mainstream service and community programs'.[184] It goes on to say that the programs are 'to be focused on creating connections between all people with disability and the communities in which they live'.[185]

In addition, a new subsection (2)(a) was inserted into section 14, which states the NDIA may provide funding to a person or entity to assist one or more participants to receive supports.[186] Subsection (2)(b) states the NDIA may provide funding to a person or entity to assist a participant under seven years of age to access supports before their NDIS plan comes into effect.[187]

The language in subsection 14(2)(a) is broad, and appears to allow greater flexibility in how the NDIA can provide funding and intervene directly in struggling markets such as remote and very remote communities.[188] The Explanatory Memorandum states subsection 14(2) was added to allow the NDIA to intervene in the market to assist participants to access supports and mitigate market challenges 'that may impede the participant from exercising choice and control'.[189] It also notes that amounts paid under section 14 are not paid directly to participants, but to a person or entity who becomes an 'NDIS provider'.[190]

The evidence at Public hearing 25 consistently identified that a viable way to improve the access of First Nations people with disability to NDIS-funded services in remote communities is through a community-based approach. This approach should build the capacity of First Nations organisations and develop a local workforce.[191] Section 14 may provide an additional lever for the NDIA to block-fund disability services, alongside individualised NDIS plans. Block-funding the community-controlled sector may be key to achieving sustainable improvements and enabling First Nations communities to develop solutions for themselves.

The community-controlled sector

We heard evidence about the preference of First Nations people with disability to receive services from First Nations Community Controlled Organisations, which are grounded in community-led service delivery and self-determination.[192] The legislative amendments to section 14 of the *NDIS Act* represent an opportunity to fund ACCOs and ACCHOs to build community capacity through additional block-funding arrangements.

Ms Turner, CEO of NACCHO, described one of the strengths of ACCOs and ACCHOs as being that they prioritise the provision of culturally safe services.[193] ACCOs and ACCHOs have a holistic view of health and wellbeing, which includes an appreciation of how First Nations cultures understand disability.[194] They are rooted in local communities, and have deep knowledge of local culture, language and families.[195]

Capacity to provide services

First Nations Community Controlled Organisations have different capacities, expertise and interest in providing NDIS services. Some ACCOs, such as NPYWC, are already providing NDIS services. With additional resources, they would be well placed to fill supply gaps in local communities.[196] However, we also heard evidence that some First Nations Community Controlled Organisations do not have the capacity to, or an interest in, providing NDIS services.[197]

Consultation is required to understand the capacity of each ACCO and ACCHO and the further support, training or investment required to build their capacity to sustainably deliver services. The cost of living as well as the cost to deliver services in remote areas are important matters to consider.

Non-First Nations providers will still have an ongoing role in service delivery. This is particularly the case in remote communities due to the NDIS market-based model, the existence of thin markets and where First Nations Community Controlled Organisations lack capacity and expertise to deliver services.[198]

Recommendation 9.5 Block funding the community-controlled sector

The National Disability Insurance Agency (NDIA) should provide block funding for First Nations Community Controlled Organisations to flexibly deliver supports and services to First Nations people with disability. This could include funding for:

- respite or accommodation in connection with their plan or disability services
- cultural supports to maintain or improve health and wellbeing
- essential supports such as food, bedding and clothing
- supports that enable access to therapy, such as transport and fuel
- translation or other services to build understanding around disability and the National Disability Insurance Scheme
- other matters as agreed by the NDIA and First Nations Community Controlled Organisations.

Cultural safety in the NDIS and cultural competency of NDIA staff

> I don't think that the NDIA understands the people of the Torres Strait Islands. They don't understand our culture or our way of life. They need to sit down respectful with us and learn.[199]

First Nations people in remote communities described a lack of cultural safety when engaging with the NDIS and NDIA employees.[200] Witnesses spoke about NDIA planners having limited understanding of the importance of Country, culture and community, particularly in remote areas.[201] Culturally competent staff were described as those who lived locally and understood First Nations culture and the remote environment.[202] Engaging with such staff was considered a 'rare' experience.[203]

Witnesses suggested a number of solutions for improving the cultural competency of NDIA staff, including:

- greater understanding of the context in which First Nations people in remote communities live, such as culture, lore, kinship, men's and women's business, traditional understanding of family, and the realities of remote living[204]
- more First Nations staff and liaison workers[205]
- access to interpreters[206]

- face-to-face meetings[207]
- involving family members or support people in planning meetings.[208]

At present, NDIA staff complete a mandatory e-learning module focused on the importance of First Nations cultural diversity.[209] However, several witnesses said cultural expertise and safety must go beyond a standard training course and be fostered throughout all levels of the NDIA.[210] Ms Turner AM explained:

> Cultural safety does not exist solely at the level of staff training, it is an organisational mind-set. Without an organisational shift in thinking and approach, no amount of staff training will deliver cultural safety for Aboriginal and Torres Strait Islander participants. Without such a shift, cultural safety is reduced to just another online, tick-and-flick training module.[211]

We heard about the benefits of community-specific cultural awareness training. Ms Bedford and Ms Atchison explained staff are required to do cultural awareness training for every community they service.[212] In the remote community of Ardyaloon, service providers must complete a cultural induction course, allowing them to access the community for 12 months.[213] This approach is effective because it is delivered by community Elders and ensures service providers understand the cultural imperatives of working in Ardyaloon community.[214]

The NDIA agreed that staff working in particular communities should undertake community-specific cultural competency training to develop local cultural acumen.[215] Mr McNaughton said the NDIA is very open to developing cultural competency and working with First Nations people, especially in remote areas, and that this might involve external agencies to help with delivery of this training.[216]

He explained the remote planning team in the Northern Territory have to get their ‘remote travel passport’, to give them the right credentials to go into remote communities.[217] This includes a detailed cultural competency course, delivered by First Nations staff in Darwin.[218] The NDIA subsequently confirmed the remote travel passport program will be formalised across Australia to ensure staff deliver the NDIS in a safe and culturally competent manner.[219] We welcome this development.

Importance of community presence

Witnesses spoke about the importance of having NDIA staff who are based in community.[220] Local staff enhance cultural safety, reduce barriers by breaking down language and cultural differences, and are better able to provide practical assistance.[221] It also improves understanding of people’s living situations and needs. Some witnesses said decision-makers based in urban centres do not understand the complexities of life for First Nations people in remote communities, and that this can affect whether supports are approved.[222] A planner’s prior experience working with First Nations people and knowledge of remote living can impact plan outcomes.[223] As Mr Geoff Davis, who is a parent of children with disability, put it:

> Someone living in other places like Geraldton would find it difficult to understand the reality of life here in the Fitzroy Valley. We will never be able to have the kinds of conversations we need to have for Tristan if there is no real understanding of the complexities of our community.[224]

We heard that a localised NDIA decision-making model would more effectively consider participants' needs, cultural factors and the variations between remote areas.[225]

Mr McNaughton acknowledged the NDIA would like to have more planners across multiple locations. Currently, the NDIA has around 85 planners to service remote areas but this does not cover every community.[226] Limited housing availability poses a challenge for staffing in remote areas, but initiatives like subsidising rent for staff can help.[227]

Measures to increase face-to-face contact with First Nations participants in remote areas include:

- employing more staff in existing planning teams in remote areas and increasing planning teams in other remote areas
- mandating a minimum number of visits planning teams must make to the remote communities they serve
- mandating a minimum number of face-to-face contacts an NDIA staff member must have for each First Nations participant living in a remote community.

First Nations NDIA staff

Several witnesses said they have never spoken to a First Nations NDIA staff member.[228] Jazsikah described the importance of having a First Nations worker present at NDIS meetings:

> When you're sitting down with a non-Indigenous person, you know, you really feel threatened … that's why a lot of people just say, "Yes, yes, yes," while, you know, if it was an Indigenous person like a liaison officer that was there, you would have felt more comfortable and it would have been less daunting.[229]

As at 31 March 2022, 2.4 per cent of the NDIA workforce self-identified as Aboriginal and/or Torres Strait Islander. No senior executive service (SES) level staff identified as Aboriginal and/or Torres Strait Islander.[230] Nine of 85 remote planners (11 per cent) identified as being from an Aboriginal or Torres Strait Islander background.[231]

NACCHO recommended the NDIA develop a strategy for building a workforce of First Nations planners to ensure at least one in each jurisdiction.[232] At Public hearing 25, Mr McNaughton confirmed they have a First Nations employment program for non-SES levels, but at that time had not recently recruited any First Nations people into senior roles.[233]

Recent developments

During Public hearing 25, June Riemer and Damian Griffis called for First Nations representation on the NDIA Board and the development of a First Nations standing committee.[234] The committee would guide the design of the NDIS in regional and remote Australia and provide advice to the NDIA on the operation of the NDIS for First Nations people.[235] Following Public hearing 25, Counsel Assisting submitted it was open to the Royal Commission to recommend that:

- section 127 of the *NDIS Act* be amended to require that the NDIA board has at least one member that self-identifies as First Nations
- the NDIA establish a standing committee to advise on the issues that affect First Nations people with disability.

In response to Counsel Assisting submissions, the Australian Government stated it supported these recommendations in principle. The Australian Government noted the upcoming NDIS review would include consideration of NDIS governance arrangements 'which may include recommended amendments to the *NDIS Act'.*

On 31 March 2023, Minister for the NDIS, the Honourable Bill Shorten MP, announced the appointment of Dr Richard Fejo, a First Nations representative, to the NDIA Board.[236] We believe this is a positive step toward the NDIA taking the measures necessary to ensure the NDIS provides appropriate supports to all First Nations people with disability eligible to become NDIS participants. This should be consolidated.

Recommendation 9.6 National Disability Insurance Agency Board

Section 127 of the *National Disability Insurance Scheme Act 2013* (Cth) should be amended to provide that the National Disability Insurance Agency Board must include at least one First Nations person at all times.

In late February 2023, the NDIA announced a new partnership with FPDN and its intention to establish a First Nations Advisory Council (FNAC).[237] In a draft letter provided to the Royal Commission, the NDIA said the purpose of the FNAC is to provide First Nations-led advice on how the NDIA can improve outcomes for First Nations people with disability.[238] Initially, it will involve a process of understanding the challenges facing First Nations peoples when accessing and using the NDIS. The FNAC will also guide the development of the NDIA's First Nations Strategy.[239]

Members include peak bodies, ACCOs, ACCHOs, representatives with lived experience of disability, advocates, the National Indigenous Australians Agency, NDIA and the Department of Prime Minister and Cabinet.[240] The NDIA has indicated an intention to include a representative member from the Torres Strait Islands, however this member has not yet been confirmed.[241] We encourage the NDIA to prioritise this appointment, so people with disability from the Torres Strait are properly represented.

Chapter 8 explores the siloed and fragmented disability policy landscape for people with disability, and makes recommendations to address these issues.

Access to interpreters

We heard access to interpreters is essential to help participants understand the NDIS and make decisions about their plans. Interpreters also help ensure cultural safety for First Nations participants.[242] Many witnesses said they have never been offered an interpreter or seen NDIS information translated into traditional language.[243]

The NDIA practice guide states when arranging a planning meeting, an interpreter should be arranged if required.[244] It also prompts planners to consider if a participant will understand the written plan, or whether another method of conveying the plan is more appropriate.[245] Counsel Assisting submitted, and we agree, that further work needs to be done to ensure the aims of the practice guide are realised in practice, such as:

- increasing staff awareness of the Practice Guide for interpreters and translation
- requiring all planners to consider and record whether an interpreter is required
- translating NDIS information and participants' plans into local First Nations languages.

Volume 6, *Enabling autonomy and access*, further discusses the importance of access to interpreters and includes relevant recommendations to address existing barriers, including for First Nations people with disability.

Participation in cultural life

> It's important for Boyzie to be able to come home because he has a young family and has not been able to spend much time with them. It's also important for him to come home because it is healing. Healing and wellbeing is connected to who we are as Torres Strait Islander people.[246]

As set out in Chapter 3, participation in cultural life is essential to social and emotional wellbeing for First Nations people with disability. The objects and general principles of the *NDIS Act* refer to supporting people with disability to participate in, and contribute to, social and economic life but do not identify supporting people with disability to participate and contribute to cultural life.[247]

Counsel Assisting submitted that recognising 'culture' in the principles that guide the operation of the NDIS would ensure that participation in 'cultural life' for First Nations people with disability is considered to be of equal importance as social and economic participation.[248] Counsel

Assisting said it was open to the Royal Commission to consider a recommendation that sections 3, 4 and 17A of the *NDIS Act,* which identify the objects and general principles, be amended to include a reference to culture.[249]

The Australian Government supported this proposed recommendation in principle, and noted the NDIS Review will consider NDIS governance arrangements, and may recommend amendments to the NDIS Act.[250]

Recommendation 9.7 Participation in cultural life

Sections 3, 4 and 17A of the *National Disability Insurance Scheme Act 2013* (Cth) should be amended to refer to participation in cultural life, in addition to participation in social and economic life.

Lack of funding for cultural supports, including Return to Country

> … being on country makes me feel happy, quiet and peaceful. I like fishing and looking for turtles. There are a few bush medicines out at Gunbalunya. There are also some marrgikbu in Gunbalunya. I like to see them when I feel unwell. Sometimes this is better than going to the doctor.[251]

The importance of connection with culture and Country was a recurring theme at Public hearing 25. The term 'return to Country' refers to First Nations people travelling back to their Country on a temporary or permanent basis. This may occur after participants have moved to urban centres to access disability support services.

There is a lack of guidance for participants and NDIA staff about recognising cultural supports and return to Country trips as reasonable and necessary supports. This has led to insufficient funding in plans for cultural supports, and rejection of requests for funding to return to Country.[252] Support for these trips often relies on the cultural awareness and willingness of planners and support coordinators.[253]

Return to Country trips are important for performing cultural obligations and practices, participating in Sorry Business, and connecting with Country, culture and community. These trips are vital for social and emotional wellbeing.[254] While leaving Country for treatment is often necessary, being off Country can lead to feeling culturally unsafe. Jody Barney, a Biri-Gubba Uragan and South Sea Islander woman and founder of Deaf Indigenous Community Consultancy Pty Ltd, said this 'is made worse through the inability or unwillingness of the NDIA to facilitate participants to return to Country on a temporary basis'.[255]

Ms Walker said First Nations people experience profound disconnection when they are forced to move off Country to access services, but the absence of funding to return to Country 'can drive even greater disengagement with services and worsening behavioural issues'.[256] Funding to support a return to Country can be pulled from a participant's 'core supports', or the participant might pay out of their own pocket. [257]

Mr McNaughton acknowledged there is great benefit for participants returning to Country, and that such trips should be funded 'where it's reasonable and necessary based on their goals and their situation'.[258] The Australian Government response to Counsel Assisting said, 'NDIS plans can already be used flexibly for transport, short term accommodation, respite and other costs that are typically associated with return to Country trips'.[259] However, some witnesses said requests to return to visit family and Country have been rejected because the NDIS 'does not fund holidays'.[260]

The NDIA accepted there is a lack of guidance for First Nations people with disability and NDIA staff about recognising cultural supports and return to Country trips as reasonable and necessary supports.[261]

The NDIA is co-designing a new policy with First Nations people and key stakeholders to ensure there is a consistent approach to return to Country funding.[262] They said the policy is being developed 'to better support participants with making connections to other government programs that fund travel to support return to Country visits, such as state government funded programs or land council funding'.[263] It is expected in 2023.[264]

Recommendation 9.8 Return to Country

In consultation with the First Nations Advisory Council, the National Disability Insurance Agency (NDIA) should:

- create a new line item in the Pricing Arrangements recognising cultural supports and return to Country trips
- develop guidelines for NDIA staff on including cultural supports and return to Country trips as reasonable and necessary supports in plans
- educate First Nations participants about the availability of cultural supports and return to Country trips included in their plans.

Role of family members

In the absence of local, skilled and First Nations-led disability services, First Nations family members often provide care to those with disability.[265] Witnesses in Public hearing 25 said that without adequate support and capacity-building, families are 'vulnerable to carers burnout'.[266] Ms McRae and Mrs Smith said:

> Caring duties put a strain on many families on the NPY Lands. People undertake very difficult care work in really challenging circumstances. They are often unsupported to do this work.[267]

We heard that support for family carers includes:

- remuneration[268]
- a flexible respite model, either on or off Country[269]
- training and information about how to care for the person with disability[270]
- assistance with caring for the person with disability.[271]

While some First Nations people with disability would prefer family to support them, rather than 'strangers', it can be complex.[272] Family members providing care may incur breaches of cultural protocols, payback if a person becomes sick or dies, and shame. [273] There can be issues around multi-generational welfare dependence, domestic violence and homelessness.[274]

Several witnesses identified the risk of exploitation, and highlighted the need for transparency, safety and security for people with disability who receive support from family members.[275]

Remuneration of family members

The NDIA's Operational Guideline on sustaining informal supports states:

> Generally, the NDIA will only fund family members to provide supports in exceptional circumstances. For example, when:
>
> - there is a risk of harm or neglect to the participant;
> - there are religious or cultural reasons for funding a family member to provide supports;
> - the participant has strong personal views, for example in relation to their privacy or dignity.
>
> The NDIA will consider the circumstances of each case, any wishes expressed by the participant, and what is reasonable to expect others to provide.[276]

Section 34(e) of the *NDIS Act* provides:

> the funding or provision of the support takes account of what it is reasonable to expect families, carers, informal networks, and the community to provide.[277]

Mr McNaughton confirmed the *NDIS Act* allows the NDIA to fund family members in exceptional circumstances.[278] When making an assessment, staff must consider: [279]

- issues around participant safety and risk
- participant choice and control over who provides personal care
- the level of training and regulation
- what is reasonable for family to provide
- other payments such as carer pensions
- the availability of registered support workers.

The NDIA does not provide specific guidance about how the 'exceptional circumstances' threshold applies to First Nations families in remote areas.[280] The Australian Government agreed consideration should be given to the development of policies and guidelines for NDIS participants to engage family members to provide supports.[281] It acknowledged the need for place-based solutions in remote service delivery, working closely with participants to access, engage or commission the supports they need.[282]

The Australian Government noted expanding the 'exceptional circumstances' threshold for family members to deliver services may create safeguarding issues that were not explored in detail during the hearing.[283] In particular, participants may lack awareness about whether they are receiving adequate or appropriate supports, and not have the knowledge or ability to make a complaint.[284] Participants may also be more reluctant to make complaints against a family member.[285] The Australian Government highlighted that the implications of family members becoming subject to the NDIS framework need to be carefully considered, including the requirement for registration for family members using restrictive practices.[286]

Witnesses at Public hearing 25 also raised these concerns.[287] While we accept these submissions, they must be balanced against the reality that many remote communities have few or no disability services, and family members currently fill the gap. This is often without training, support, oversight or respite. Many of the safeguarding issues identified by the Australian Government may already exist for these participants.

The complexities and concerns about funding for family members to provide disability supports is a compelling reason to take urgent steps to build the capacity of the First Nations community-controlled sector, and a suitably skilled local workforce in remote communities.

Recommendation 9.9 Criteria for funding family supports

The National Disability Insurance Agency (NDIA), the First Nations Advisory Council and First Nations Community Controlled Organisations should co-design policy guidelines on funding for First Nations family members to provide supports to participants in remote communities. Any policy guidelines should consider:

- the risk of financial exploitation, the need for a regulatory framework and oversight, and whether a similar approach would apply to non-First Nations carers in remote communities in similar situations
- the availability of suitable services, including culturally safe services
- training for NDIA staff on how to apply the policy guidelines, including how staff can support family to apply to be paid for the care provided
- building awareness of the circumstances in which participants and their families can apply to be paid
- how to build the capacity of family and community members to become part of the local workforce, such as trained support or community workers, which may include connecting family members with a First Nations Community Controlled Organisation.

Endnotes

1 National Disability Insurance Agency, First Nations participants data download, web page, December 2022. <data.ndis.gov.au/data-downloads>

2 Exhibit 25-95, ‘Statement of Scott McNaughton’, 15 June 2022, at [16].

3 Transcript, Patrick Griffin (Counsel Assisting), 13 July 2022, Public hearing 25, P-175 [17–26]; Transcript, Geoff Davis, Public hearing 25, 13 July 2022, P-194 [16]; ‘Statement of Patricia Turner’, Public hearing 25, [14], [53–57], [103]; Transcript, Patricia Turner, Public hearing 25, 14 July 2022, P-297 [20].

4 See for example, Exhibit 25-46, ‘Statement of Topsy (Stella) Jackamarra’, 22 June 2022, at [28–33]; Exhibit 25-64, ‘Statement of Emily Carter and Lauren Rice’, 20 June 2022, at [46]; Transcript of Emily Carter, Public hearing 25, 13 July 2022, P-251 [26]–[32].

5 Exhibit 15-11.20, DRC.1000.0007.1349, pp 151–152.

6 Exhibit 15-11.21, DRC.1000.0007.1894, pp 531, 544, 555.

7 Exhibit 15-11.21, DRC.1000.0007.1894, p 557.

8 Exhibit 25-14, ‘Statement of Paulette’, 11 May 2022, at [29]; Exhibit 25-34, ‘Statement of Joanne Houghton’, 21 June 2022, at [37]; Exhibit 25-19, ‘Joint statement of Kunmanara (Margaret) Smith and Kim McRae’, 21 June 2022, at [60]; Exhibit 25-64, ‘Joint Statement of Emily Carter and Dr Lauren Rice’, 20 June 2022, at [63].

9 Exhibit 25-41, ‘Statement of Geoff Davis’, 15 June 2022 at [51] and [54]; Exhibit 25-34, ‘Statement of Joanne Houghton’, 21 June 2022, at [42–43]; Exhibit 25-64, ‘Joint Statement of Emily Carter and Dr Lauren Rice’, 20 June 2022, at [64]; Exhibit 25-19, ‘Joint statement of Kunmanara (Margaret) Smith and Kim McRae’, 21 June 2022, at [57]; Exhibit 25-8, ‘Statement of ‘Joan’’, 22 June 2022, at [36](d); Exhibit 25-1, ‘Statement of ‘Daisy’’, 21 June 2022, at [39], [53].

10 Exhibit 25-64, ‘Joint statement of Emily Carter and Dr Lauren Rice’, 20 June 2022, at [56]; Exhibit 25-15, ‘Statement of Emily Sherwood’, 24 June 2022, at [29].

11 Exhibit 25-64, ‘Joint statement of Emily Carter and Dr Lauren Rice’, 20 June 2022, at [57]; Transcript, Jenny Bedford, Public hearing 25, 14 July 2022, P-312 [28–31].

12 Exhibit 25-63, ‘Transcript of pre-recorded video statement of Mudge (Eric) Bedford’, 3 June 2022, P-12 [15–25]; Exhibit 25-43, TRA.3000.0013.0047, P-9 [12–17]; Exhibit 25-34, ‘Statement of Joanne Houghton’, 21 June 2022, at [48]; Exhibit 25-64, ‘Joint statement of Emily Carter and Dr Lauren Rice’, 20 June 2022, at [66–67].

13 Transcript, Bakoi Namok, Public hearing 25, 12 July 2022, P-169 [9–14]; Exhibit 25-23, ‘Statement of Beth Walker’, 1 June 2022, at [16].

14 Exhibit 25-15, ‘Statement of Emily Sherwood’, 24 June 2022, at [40–44], [55]; Exhibit 25-1, ‘Statement of ‘Daisy’’, 21 June 2022, at [34], [26–31]; Exhibit 25-46, ‘Statement of Stella (Topsy) Jackamarra’, 22 June 2022, at [45–86]; Exhibit 25-14, ‘Statement of Paulette’, 11 May 2022, at [15]; Exhibit 25-34, ‘Statement of Joanne Houghton’, 21 June 2022, at [38]; Transcript, ‘Joan’, Public hearing 25,11 July 2022, P-53 [36–42]; Exhibit 25-19, ‘Joint Statement of Kunmanara (Margaret) Smith and Kim McRae’, 21 June 2022, at [59]; Exhibit 25-92, ‘Statement of Damian Griffis and June Riemer’, 23 June 2022, at [57].

15 Exhibit 25-19, ‘Joint Statement of Kunmanara (Margaret) Smith and Kim McRae’, 21 June 2022, at [66].

16 Exhibit 25-1, ‘Statement of ‘Daisy’’, 21 June 2022, at [32], [34], [41]; Exhibit 25-15, ‘Statement of Emily Sherwood’, 24 June 2022, at [47] and [62]; Exhibit 25-34, ‘Statement of Stella (Topsy) Jackamarra’, 22 June 2022, at [88–89].

17 Exhibit 25-14, ‘Statement of Paulette’, 11 May 2022, at [29].

18 Exhibit 25-43, TRA.3000.0013.0047, P-2 [15–20], [30–37].

19 Exhibit 25-43, TRA.3000.0013.0047, P-7 [40–49].

20 Exhibit 25-43, TRA.3000.0013.0047, P-8 [30–39], P-10 [36–40], P-11 [9–15].

21 Exhibit 25-64, ‘Joint Statement of Emily Carter and Dr Lauren Rice’, 20 June 2022, at [2–3], [10].

22 Exhibit 25-64, ‘Joint Statement of Emily Carter and Dr Lauren Rice’, 20 June 2022, at [63].

23 Names changed to protect identity; Exhibit 25-1, ‘Statement of ‘Daisy’’, 21 June 2022, at [32], [34], [39–41], [46–50], [59], Transcript, ‘Daisy’, Public hearing 25, 11 July 2022, P-21 [38–47], P-22 [1–36], P-23 [24–26].

24 Exhibit 25-1, ‘Statement of ‘Daisy’’, 21 June 2022, at [8–10].

25 Exhibit 25-1, ‘Statement of ‘Daisy’’, 21 June 2022, at [13].
26 Exhibit 25-1, ‘Statement of ‘Daisy’’, 21 June 2022, at [51], [53].
27 Exhibit 25-1, ‘Statement of ‘Daisy’’, 21 June 2022, at [53].
28 Exhibit 25-1, ‘Statement of ‘Daisy’’, 21 June 2022, at [54–55].
29 Exhibit 25-1, ‘Statement of ‘Daisy’’, 21 June 2022, at [56].
30 Exhibit 25-19, ‘Joint statement of Kunmanara (Margaret) Smith and Kim McRae’, 21 June 2022, at [23].
31 Australian Government, ‘Land areas of States and Territories’, Geoscience Australia, web page, 28 April 2023. <www.ga.gov.au/scientific-topics/national-location-information/dimensions/area-of-australia-states-and-territories>
32 Exhibit 25-19, ‘Joint statement of Kunmanara (Margaret) Smith and Kim McRae’, 21 June 2022, at [18–19], [28].
33 Exhibit 25-19, ‘Joint statement of Kunmanara (Margaret) Smith and Kim McRae’, 21 June 2022, at [187–190].
34 Exhibit 25-19, ‘Joint statement of Kunmanara (Margaret) Smith and Kim McRae’, 21 June 2022, at [57]; Exhibit 25-34, ‘Statement of Joanne Houghton’, 21 June 2022, at [43]; Exhibit 25-41, ‘Statement of Geoff Davis’, 15 June 2022, at [51].
35 See, for example, Exhibit 25-34, ‘Statement of Joanne Houghton’, 21 June 2022, at [31]; Exhibit 25-64, ‘Joint statement of Emily Carter and Dr Lauren Rice’, 20 June 2022, at [34]; Exhibit 25-19, ‘Joint statement of Kunmanara (Margaret) Smith and Kim McRae’, 21 June 2022, at [124]. Exhibit 25-23, ‘Statement of Beth Walker’, 1 June 2022, at [23]; Transcript, Jenny Bedford, Public hearing 25, 14 July 2022, P-318 [7–10].
36 Royal Commission community engagement, Torres Strait Islands, August 2022.
37 Royal Commission community engagement, Torres Strait Islands, August 2022.
38 Royal Commission community engagement, Torres Strait Islands, August 2022.
39 Royal Commission community engagement, Northern Territory, May 2021.
40 Royal Commission community engagement, Northern Territory, May 2021.
41 Royal Commission community engagement, Northern Territory, May 2021.
42 Exhibit 25-107, ‘Statement of Kitsa Papadopoulos’, 14 June 2022, at [13]; Transcript, Kitsa Papadopoulos, Public hearing 25, 14 July 2022, P-335 [27–28].
43 Exhibit 25-107, ‘Statement of Kitsa Papadopoulos’, 14 June 2022 at [13]. See also Exhibit 25-130, CTD.8000.0032.0596, pp 9, 18.
44 Exhibit 25-107, ‘Statement of Kitsa Papadopoulos’, 14 June 2022 at [13].
45 Exhibit 25-1, ‘Statement of ‘Daisy’’, 21 June 2022, at [29].
46 Exhibit 25-15, ‘Statement of Emily Sherwood’, 24 June 2022, at [40–44], [55]; Exhibit 25-1, ‘Statement of ‘Daisy’’, 21 June 2022, at [34], [26–31]; Exhibit 25-46, ‘Statement of Stella (Topsy) Jackamarra’, 22 June 2022, at [45–86]; Exhibit 25-14, ‘Statement of Paulette’, 11 May 2022, at [15]; Exhibit 25-34, ‘Statement of Joanne Houghton’, 21 June 2022, at [38]; Transcript, ‘Joan’, Public hearing 25,11 July 2022, P-53 [36–42]; Exhibit 25-19, ‘Joint statement of Kunmanara (Margaret) Smith and Kim McRae’, 21 June 2022, at [59]; Exhibit 25-92, ‘Statement of Damian Griffis and June Riemer’, 23 June 2022, at [57].
47 Exhibit 25-45, ‘Transcript of pre-recorded evidence of Ronita Jackamarra’, 29 April 2022, P-2 [19–50], P3 [1–6].
48 Exhibit 25-46, ‘Statement of Stella (Topsy) Jackamarra’, 22 June 2022, at [49], [59].
49 Exhibit 25-45, ‘Transcript of pre-recorded evidence of Ronita Jackamarra’, 29 April 2022, P-2 [16].
50 Exhibit 25-46, ‘Statement of Stella (Topsy) Jackamarra’, 22 June 2022, at [52]
51 Exhibit 25-46, ‘Statement of Stella (Topsy) Jackamarra’, 22 June 2022, at [52–57].
52 Transcript, Scott McNaughton, Public hearing 25, 15 July 2022, P-365 [33].
53 Transcript, Scott McNaughton, Public hearing 25, 15 July 2022, P-366 [33–35].
54 Fiona Coglin, Submission, 24 June 2020, SUB.001.00347, p 1.
55 Exhibit 25-33, ‘Statement of Bakoi Namok’, 9 July 2022, at [46], [50]; Exhibit 25-63, TRA.3000.0013.0021, P-5 [1–12], P-10 [20–38]; Exhibit 25-19, ‘Joint statement of Kunmanara (Margaret) Smith and Kim McRae’, at [153–154], [156], [158]; Exhibit 25-92, ‘Statement of Damian Griffis and June Riemer’, at [61]; Exhibit 25-12, ‘Statement of Jody Ann Barney’, at [28], [31].
56 Exhibit 25-63, TRA.3000.0013.0021, P-4 [29–45].
57 Exhibit 25-63, TRA.3000.0013.0021, P-4 [31–35]

58 Exhibit 25-43, TRA.3000.0013.0047, P-3 [16–49] – P-4 [1–16], P-10 [7–22].

59 Exhibit 25-43, TRA.3000.0013.0047, P-10 [7–12].

60 Exhibit 25-43, TRA.3000.0013.0047, P-3 [39–49], P-4 [10–16], P-10 [7–22].

61 Exhibit 25-64, ‘Joint statement of Emily Carter and Dr Lauren Rice’, 20 June 2022, at [69–70].

62 Exhibit 25-19, ‘Joint Statement of Kunmanara (Margaret) Smith and Kim McRae’, 21 June 2022, at [153–154], [158]

63 Exhibit 25-19, ‘Joint statement of Kunmanara (Margaret) Smith and Kim McRae’, 21 June 2022, at [156].

64 Exhibit 25-23, ‘Statement of Beth Walker’, 1 June 2022, at [26].

65 Exhibit 25-23, ‘Statement of Beth Walker’, 1 June 2022, at [46].

66 Exhibit 25-23, ‘Statement of Beth Walker’, 1 June 2022, at [48].

67 Exhibit 25-19, ‘Joint Statement of Kunmanara (Margaret) Smith and Kim McRae’, 21 June 2022, at [66].

68 Transcript, June Riemer, Public hearing 25, 14 July 2022, P-276 [46–47], P-277 [2–37].

69 Transcript, Kim McRae, Public hearing 25, 12 July 2022, P-116 [17–20].

70 Transcript, Kim McRae, Public hearing 25, 12 July 2022, P-116 [20–22]; Exhibit 25-64, ‘Joint Statement of Emily Carter and Dr Lauren Rice’, 20 June 2022, at [80].

71 Exhibit 25-23, ‘Statement of Beth Walker’, 1 June 2022, at [33].

72 Submissions of Counsel Assisting the Royal Commission following Public hearing 25, 20 March 2023, SUBM.0042.0001.0024, p 92 [305].

73 Transcript, Kim McRae, Public hearing 25, 12 July 2022, P-130 [33–36].

74 Exhibit 25-33, ‘Statement of Bakoi Namok’, 9 July 2022, at [39–54].

75 Exhibit 25-33, ‘Statement of Bakoi Namok’, 9 July 2022, at [42].

76 Exhibit 25-33, ‘Statement of Bakoi Namok’, 9 July 2022, at [44–45].

77 Transcript, Bakoi Namok, Public hearing 25, 12 July 2022, P-166 [13–26].

78 Exhibit 25-104, CTD.8000.0038.2137, p 1.

79 Exhibit 25-1, ‘Statement of ‘Daisy’’, 21 June 2022, at [12], [28–29]; Exhibit 25-15, ‘Statement of Emily Sherwood’, 24 June 2022, at [27–28], [68]; Exhibit 25-8, ‘Statement of ‘Joan’’, 22 June 2022, at [79–80].

80 Exhibit 25-15, ‘Statement of Emily Sherwood’, 24 June 2022, at [27].

81 Exhibit 25-46, ‘Statement of Stella (Topsy) Jackamarra’, 22 June 2022, at [41]; Exhibit 25-43, TRA.3000.0013.0047, 8 June 2022, at P-6 [17–23]; Exhibit 25-34, ‘Statement of Joanne Houghton’, 21 June 2022, at [70–72]; Exhibit 25-19, ‘Joint statement of Kunmanara (Margaret) Smith and Kim McRae’, 21 June 2022, at [83], [151]; Transcript, Kunmanara (Margaret) Smith, Public hearing 25, 12 July 2022, P124 [10–12], [29–30].

82 Transcript, Emily Carter, Public hearing 25, 13 July 2022, P-256 [17–27], Exhibit 25-19, ‘Joint statement of Kunmanara (Margaret) Smith and Kim McRae’, 21 June 2022, at [131–142].

83 Exhibit 25-84, ‘Statement of Patricia Turner’, 27 June 2022, at [44].

84 Transcript, Kim McRae, Public hearing 25, 12 July 2022, P-118 [26–27]; Exhibit 25-135, CTD.8000.0032.0450, p 7.

85 See, for example, Exhibit 25-92, ‘Statement of Damian Griffis and June Riemer’, 23 June 2022, at [45].

86 Exhibit 25-1, ‘Statement of ‘Daisy’’, 21 June 2022, at [12]; Exhibit 25-15, ‘Statement of Emily Sherwood’, 24 June 2022, at [52], [57]; Exhibit 25-33, ‘Statement of Bakoi Namok’, 9 July 2022, at [51–52].

87 Royal Commission community engagement, Northern Territory, February 2021.

88 Exhibit 25-95, ‘Statement of Scott McNaughton’, 15 June 2022, at [38].

89 Exhibit 25-95, ‘Statement of Scott McNaughton’, 15 June 2022, at [39].

90 Exhibit 25-159, ‘Supplementary statement of Scott McNaughton and Kitsa Papadopoulos’, 29 July 2022, at [22]; Transcript, Scott McNaughton, Public hearing 25, 14 July 2022, P-341 [1–7].

91 Exhibit 25-95, ‘Statement of Scott McNaughton’, 15 June 2022, at [97(a)].

92 Exhibit 25-95, ‘Statement of Scott McNaughton’, 15 June 2022, at [43–44].

93 Exhibit 25-95, ‘Statement of Scott McNaughton’, 15 June 2022, at [45].

94 Exhibit 25-78, ‘Joint statement of Jenny Bedford and Cassie Atchison’, 17 June 2022, at [29–30].

95 Exhibit 25-78, ‘Joint statement of Jenny Bedford and Cassie Atchison’, 17 June 2022, at [30–31].

96 Exhibit 25-78, ‘Joint statement of Jenny Bedford and Cassie Atchison’, 17 June 2022, at [35], [46].

97 Transcript, Cassie Atchison, Public hearing 25, 14 July 2022, P-298 [31–35].

98 Transcript, Jenny Bedford, Public hearing 25, 14 July 2022, P-308 [42–46].

99 Exhibit 25-64, ‘Joint Statement of Emily Carter and Dr Lauren Rice’, 20 June 2022, at [45]. Marra Worra Worra, an Aboriginal resource agency, recently took on the RCC contract, which is the first time since the NDIS was rolled out in the region: Exhibit 25-64, ‘Joint Statement of Emily Carter and Dr Lauren Rice’, 20 June 2022, at [73].

100 Exhibit 25-19, ‘Joint statement of Kunmanara (Margaret) Smith and Kim McRae’, 21 June 2022, at [113–115], [119].

101 Exhibit 25-19, ‘Joint statement of Kunmanara (Margaret) Smith and Kim McRae’, 21 June 2022, at [120–123].

102 Exhibit 25-19, ‘Joint statement of Kunmanara (Margaret) Smith and Kim McRae’, 21 June 2022, at [121].

103 Exhibit 25-19, ‘Joint statement of Kunmanara (Margaret) Smith and Kim McRae’, 21 June 2022, at [122].

104 Exhibit 25-19, ‘Joint statement of Kunmanara (Margaret) Smith and Kim McRae’, 21 June 2022, at [123].

105 See, for example, Transcript, Patricia Turner, Public hearing 25, 14 July 2022, P-301 [29–30]; Transcript, Jenny Bedford, Public hearing 25, 14 July 2022, P-308 [30–33].

106 For example, MWRC recommended five-year funding for the RCC program in the Fitzroy Valley: Exhibit 25-64, ‘Joint statement of Emily Carter and Dr Lauren Rice’, 20 June 2022, at [47]; Exhibit 25-77, MWRC.9999.0001.0001, p 9 (Recommendation 1).

107 Exhibit 25-78, ‘Joint statement of Jenny Bedford and Cassie Atchison’, 17 June 2022, at [63(a)]; Exhibit 25-19, ‘Joint statement of Kunmanara (Margaret) Smith and Kim McRae’, 21 June 2022, at [121].

108 Transcript, Patricia Turner, Public hearing 25, 14 July 2022, P-301 [31–35]; Exhibit 25-19, ‘Joint statement of Kunmanara (Margaret) Smith and Kim McRae’, 21 June 2022, at [115], [118]; Transcript, Cassie Atchison, Public hearing 25, 14 July 2022, P-299 [11–12].

109 Submissions by the Australian Government in response to Counsel Assisting’s submissions in Public hearing 25, 14 December 2022, SUBM.0042.0001.0001, p 18 [68].

110 Submissions by the Australian Government in response to Counsel Assisting’s submissions in Public hearing 25, 14 December 2022, SUBM.0042.0001.0001, p 18 [69].

111 Submissions by the Australian Government in response to Counsel Assisting’s submissions in Public hearing 25, 14 December 2022, SUBM.0042.0001.0001, p 19 [70].

112 Submissions by the Australian Government in response to Counsel Assisting’s submissions in Public hearing 25, 14 December 2022, SUBM.0042.0001.0001, p 19 [71].

113 Submissions by the Australian Government in response to Counsel Assisting’s submissions in Public hearing 25, 14 December 2022, SUBM.0042.0001.0001, p 19 [71].

114 Exhibit 25-19, ‘Joint statement of Kunmanara (Margaret) Smith and Kim McRae’, 21 June 2022, at [162].

115 Exhibit 25-19, ‘Joint statement of Kunmanara (Margaret) Smith and Kim McRae’, 21 June 2022, at [50], [193]; Transcript, Kim McRae, Public hearing 25, 12 July 2022, P-115 [1–13].

116 Exhibit 25-19, ‘Joint statement of Kunmanara (Margaret) Smith and Kim McRae’, 21 June 2022, at [160], [162].

117 Transcript, Kim McRae, Public hearing 25, 12 July 2022, P-121 [27–28].

118 Exhibit 25-19, ‘Joint Statement of Kunmanara (Margaret) Smith and Kim McRae’, 21 June 2022, at [100].

119 Exhibit 25-19, ‘Joint Statement of Kunmanara (Margaret) Smith and Kim McRae’, 21 June 2022, at [96–97].

120 Exhibit 25-19, ‘Joint Statement of Kunmanara (Margaret) Smith and Kim McRae’, 21 June 2022, at [96–97].

121 Transcript, Kim McRae, Public hearing 25, 12 July 2022, P-121 [28–30].

122 Transcript, Kim McRae, Public hearing 25, 12 July 2022, P-121 [36–43]; Exhibit 25-19, ‘Joint statement of Kunmanara (Margaret) Smith and Kim McRae’, 21 June 2022, at [105–106]

123 Transcript, Kim McRae, Public hearing 25, 12 July 2022, P-122 [5–7].

124 Transcript, Kim McRae, Public hearing 25, 12 July 2022, P-121 [40–43].

125 Transcript, Kim McRae, Public hearing 25, 12 July 2022, P-121 [45-46]; Exhibit 25-19, ‘Joint statement of Kunmanara (Margaret) Smith and Kim McRae’, 21 June 2022, at [105–106].

126 Transcript, Scott McNaughton, Public hearing 25, 14 July 2022, P-333 [15–17].

127 Transcript, Scott McNaughton, Public hearing 25, 14 July 2022, P-333 [17–19].

128 Submissions by the Australian Government in response to Counsel Assisting's submissions in Public hearing 25, 14 December 2022, SUBM.0042.0001.0001, p 7 [23].

129 Submissions by the Australian Government in response to Counsel Assisting's submissions in Public hearing 25, 14 December 2022, SUBM.0042.0001.0001, p 7 [24].

130 Submissions by the Australian Government in response to Counsel Assisting's submissions in Public hearing 25, 14 December 2022, SUBM.0042.0001.0001, p 8 [25].

131 Submissions by the Australian Government in response to Counsel Assisting's submissions in Public hearing 25, 14 December 2022, SUBM.0042.0001.0001, p 9 [29].

132 Exhibit 25-34, 'Statement of Joanne Houghton', 21 June 2022, at [31(a)].

133 Exhibit 25-131, CTD.8000.0032.0596, p 30.

134 Exhibit 25-131, CTD.8000.0032.0596, p 30.

135 Exhibit 25-163, CTD.9999.0079.0089, p 28; Exhibit 25-84, 'Statement of Patricia Turner', 27 June 2022, at [68], [71]; Exhibit 25-78, 'Joint statement of Jenny Bedford and Cassie Atchison', 17 June 2022, at [68]; Exhibit 25-131, 'CTD.8000.0032.0596', p 45.

136 Exhibit 25-34, 'Statement of Joanne Houghton', 21 June 2022, at [27]; Transcript, Cassie Atchison, Public hearing 25, 14 July 2022, P-318 [21–26].

137 Victorian Aboriginal Child Care Agency, Response to *The experience of First Nations people with disability in Australia issues paper,* 11 October 2020, ISS.001.0086, p 14; Jill Gallagher, Victorian Aboriginal Community Controlled Health Organisation, Submission in response to *The experience of First Nations people with disability in Australia issues paper,* 16 October 2020, ISS.001.00493, p 11.

138 Transcript, Patricia Turner, Public hearing 25, 14 July 2022, P-306 [30–37].

139 Exhibit 25-84, 'Statement of Patricia Turner', 27 June 2022, at [102–103].

140 See, for example, Exhibit 25-12, 'Statement of Jody Ann Barney', 11 June 2022, at [35–36]; Exhibit 2592, 'Statement of Damian Griffis and June Riemer', 23 June 2022, at [71], [73].

141 Exhibit 25-78, 'Joint statement of Jenny Bedford and Cassie Atchison', 17 June 2022, at [70]; Exhibit 2564, 'Joint statement of Emily Carter and Dr Lauren Rice', 20 June 2022, at [45](c).

142 Exhibit 25-64, 'Joint statement of Emily Carter and Dr Lauren Rice', 20 June 2022, at [70]; Transcript, Jenny Bedford, Public hearing 25, 14 July 2022, P-312 [27–35].

143 Exhibit 25-64, 'Joint statement of Emily Carter and Dr Lauren Rice', 20 June 2022, at [46]; Transcript, Emily Carter, Public hearing 25, 13 July 2022, P-251 [26–32].

144 National Disability Services, Submission in response to *The experience of First Nations people with disability in Australia issues paper*, 16 October 2020, ISS.001.00496, p 3.

145 Exhibit 25-84, 'Statement of Patricia Turner', 27 June 2022, at [98].

146 Exhibit 25-84, 'Statement of Patricia Turner', 27 June 2022, at [99].

147 Transcript, Scott McNaughton, Public hearing 25, 15 July 2022, P-344 [9–35].

148 Transcript, Scott McNaughton, Public hearing 25, 14 July 2022, P-344 [9–35].

149 Council of Australian Governments Disability Reform Council, 'Meeting of the COAG Disability Reform Council', communique, Perth, 13 December 2019, p 2; Exhibit 25-107, 'Statement of Kitsa Papadopoulos', 14 June 2022 at [24].

150 Exhibit 25-107, 'Statement of Kitsa Papadopoulos', 14 June 2022, at [25–26].

151 Transcript, Kitsa Papadopoulos, Public hearing 25, 15 July 2022, P-348 [43–46], P-349 [1].

152 Transcript, Kitsa Papadopoulos, Public hearing 25, 15 July 2022, P-357 [17–18].

153 National Disability Insurance Agency, *Thin market trials,* Final evaluation report, December 2022, pp 7, 52.

154 National Disability Insurance Agency, *Thin market trials,* Final evaluation report, December 2022, pp 7, 52.

155 Exhibit 25-130, CTD.8000.0032.0348, p 5.

156 Exhibit 25-95, 'Statement of Scott McNaughton', 15 June 2022, at [141–142].

157 Exhibit 25-130, CTD.8000.0032.0348, p 16.

158 Transcript, Scott McNaughton, Public hearing 25, 15 July 2022, P-371 [6–7].

159 Exhibit 25-40, 'Statement of Marmingee Hand', 4 July 2022, at [51].

160 Exhibit 15-11.21, DRC.1000.0007.1894, pp 531–61.

161 Exhibit 25-107, 'Statement of Kitsa Papadopoulos', 14 June 2022 at [24-30]; Exhibit 25-95, 'Statement of Scott McNaughton', 15 June 2022, at [79–84].

162 National Disability Insurance Agency, *Thin market trials,* Final evaluation report, December 2022, p 20.

163 Submissions by the Australian Government in response to Counsel Assisting’s submissions in Public hearing 25, 14 December 2022, SUBM.0042.0001.0001, p 4 [9].

164 Submissions by the Australian Government in response to Counsel Assisting’s submissions in Public hearing 25, 14 December 2022, SUBM.0042.0001.0001, p 5 [13].

165 Submissions by the Australian Government in response to Counsel Assisting’s submissions in Public hearing 25, 14 December 2022, SUBM.0042.0001.0001, p 5 [13].

166 Transcript, Ronald Sackville (Chair), Public hearing 25, 14 July 2022, P-372 [27–30].

167 Transcript, Scott McNaughton, Public hearing 25, 15 July 2022, P-372 [36–41].

168 Transcript, Andrea Mason (Commissioner), Public hearing 25, 14 July 2022, P-336 [5–9].

169 Transcript, Andrea Mason (Commissioner), Public hearing 25, 14 July 2022, P-336–37 [29–47], [1–4].

170 Exhibit 25-92, ‘Statement of Damian Griffis and June Riemer’, 23 June 2022, at [65]; Transcript, June Riemer, Public hearing 25, 14 July 2022, P-271 [1–6].

171 Exhibit 25-92, ‘Statement of Damian Griffis and June Riemer’, 23 June 2022, at [65]; Transcript, June Riemer, Public hearing 25, 14 July 2022, P-271 [1–6].

172 Transcript, June Riemer, Public hearing 25, 14 July 2022, P-271 [8–12].

173 Transcript, Kitsa Papadopoulos, Public hearing 25, 14 July 2022, P-336 [26–27].

174 Transcript, Scott McNaughton, Public hearing 25, 15 July 2022, P-372 [11].

175 Submissions by the Australian Government in response to Counsel Assisting’s submissions in Public hearing 25, 14 December 2022, SUBM.0042.0001.0001, p 15 [55].

176 Submissions by the Australian Government in response to Counsel Assisting’s submissions in Public hearing 25, 14 December 2022, SUBM.0042.0001.0001, p 16 [56].

177 Exhibit 15-11.20, DRC.1000.0007.1349, pp 152–53.

178 Exhibit 25-159, ‘Supplementary statement of Scott McNaughton and Kitsa Papadopoulos’, 29 July 2022.

179 Transcript, Kitsa Papadopoulos, Public hearing 25, 14 July 2022, P-339 [16–21].

180 Exhibit 25-159, ‘Supplementary statement of Scott McNaughton and Kitsa Papadopoulos’, 29 July 2022, at [19].

181 Exhibit 25-159, ‘Supplementary statement of Scott McNaughton and Kitsa Papadopoulos’, 29 July 2022, at [17–18].

182 Transcript, Scott McNaughton, Public hearing 25, 14 July 2022, P-339 [43–45], P-340 [21–22]. See also P-334–58.

183 Ernst and Young, *Independent review of the NDIS Act,* Final Report, December 2015.

184 Explanatory Memorandum, National Disability Insurance Scheme Amendment (Participant Service Guarantee and Other Measure) Bill 2021 (Cth), p 35.

185 Explanatory Memorandum, National Disability Insurance Scheme Amendment (Participant Service Guarantee and Other Measure) Bill 2021 (Cth), p 35.

186 *National Disability Insurance Scheme Act 2013* (Cth), s 14 (2)(a).

187 *National Disability Insurance Scheme Act 2013* (Cth), s 14 (2)(b).

188 *National Disability Insurance Scheme Act 2013* (Cth), s 14; Explanatory Memorandum, National Disability Insurance Scheme Amendment (Participant Service Guarantee and Other Measure) Bill 2021 (Cth), pp 35–36.

189 Explanatory Memorandum, National Disability Insurance Scheme Amendment (Participant Service Guarantee and Other Measure) Bill 2021 (Cth), p 35–36.

190 Explanatory Memorandum, National Disability Insurance Scheme Amendment (Participant Service Guarantee and Other Measure) Bill 2021 (Cth), p 35.

191 See, for example, Exhibit 25-92, ‘Statement of Damian Griffis and June Riemer’, 23 June 2022, at [64–68]; Exhibit 25-84, ‘Statement of Patricia Turner’, 27 June 2022, at [95–97] Rec [162]; Exhibit 25-19, ‘Joint statement of Kunmanara (Margaret) Smith and Kim McRae’, 21 June 2022, at [69–78], [192–195]; Exhibit 25-21, NPY.0001.0001.0001, p 44; Exhibit 25-40, ‘Statement of Marmingee Hand’, 4 July 2022, at [51]; Exhibit 25-41, ‘Statement of Geoff Davis’, 15 June 2022, at [61]; Exhibit 25-46, ‘Statement of Stella (Topsy) Jackamarra’, 22 June 2022, at [120–25]; Exhibit 25-34, ‘Statement of Joanne Houghton’, 21 June 2022, at [117], [119]; Exhibit 25-64, ‘Joint statement of Emily Carter and Dr Lauren Rice’, 20 June 2022, at [34], [40–41] [43-46]; Exhibit 25-77, MWRC.9999.0001.0001, pp 8, 9, 11–12, 67–73, 92; Exhibit 25-78, ‘Joint statement of Jenny Bedford and Cassie Atchison’, 17 June 2022, at [26–44].

192 Exhibit 25-84, ‘Statement of Patricia Turner’, 27 June 2022, at [92–93].

193 Exhibit 25-84, ‘Statement of Patricia Turner’, 27 June 2022, at [23], [51].

194 Transcript, Jenny Bedford, Public hearing 25, 14 July 2022, P-302 [40–45], P-303 [1–17].

195 Transcript, Kim McRae, Public hearing 25, 12 July 2022, P-126 [29–33]; Transcript, June Riemer, Public hearing 25, 14 July 2022, P-267, P-270 [27–35].

196 Transcript, Kim McRae, Public hearing 25, 12 July 2022, P-126 [29–33].

197 Exhibit 25-86, EXP.0029.0004.0001, pp 14–15.

198 Transcript, Kitsa Papadopoulos, Public hearing 25, 15 July 2022, P-394 [4–11].

199 Exhibit 25-33, ‘Statement of Bakoi Namok’, 9 July 2022, at [53].

200 Exhibit 25-43, TRA.3000.0013.0047, P-5 [16–20]; Exhibit 25-34, ‘Statement of Joanne Houghton’, 21 June 2022, at [74]; Exhibit 25-33, ‘Statement of Bakoi Namok’, 9 July 2022, at [53–54]; Exhibit 25-19, ‘Joint statement of Kunmanara (Margaret) Smith and Kim McRae’, 21 June 2022, at [141].

201 See, for example, Transcript, Jody Barney, Public hearing 25, 11 July 2022, P-67 [13–15]; Exhibit 25-34, ‘Statement of Joanne Houghton’, 21 June 2022, at [72].

202 Transcript, ‘Joan’, Public hearing 25, 11 July 2022, P-50 [19–21]; Exhibit 25-23, ‘Statement of Beth Walker’, 1 June 2022, at [67–68].

203 Exhibit 25-92, ‘Statement of Damian Griffis and June Riemer’, 23 June 2022, at [33]; Exhibit 25-23, ‘Statement of Beth Walker’, 1 June 2022, at [68].

204 Exhibit 25-19, ‘Joint statement of Kunmanara (Margaret) Smith and Kim McRae’, 21 June 2022, at [125]; Exhibit 25-15, ‘Statement of Emily Sherwood’, 24 June 2022, at [70]; Exhibit 25-63, TRA.3000.0013.0021, P-13 [21–30], P-14 [1–9].

205 Exhibit 25-23, ‘Statement of Beth Walker’, 1 June 2022, at [68]; Exhibit 25-43, TRA.3000.0013.0047, P5 [34–49].

206 Exhibit 25-34, ‘Statement of Joanne Houghton’, 21 June 2022, at [113]; Exhibit 25-92, ‘Statement of Damian Griffis and June Riemer’, 23 June 2022, at [52–53]; Exhibit 25-43, TRA.3000.0013.0047, P-5 [31–34].

207 Exhibit 25-46, ‘Statement of Stella (Topsy) Jackamarra’, 22 June 2022, at [131]; Exhibit 25-43, TRA.3000.0013.0047, P-7 [23–28].

208 Exhibit 25-46, ‘Statement of Stella (Topsy) Jackamarra’, 22 June 2022, at [132]; Exhibit 25-15, ‘Statement of Emily Sherwood’, 24 June 2022, at [18]; Transcript, Jody Barney, Public hearing 25, 11 July 2022, P-67 [15–17].

209 As at 30 April 2022, 89.5 per cent of NDIA staff had completed the module ‘Celebrating Diversity: First Nations Cultures’: Exhibit 25-95, ‘Statement of Scott McNaughton’, 15 June 2022, at [86–87]. See also Submissions by the Australian Government in response to Counsel Assisting’s submissions in Public hearing 25, 14 December 2022, SUBM.0042.0001.0001, p 22 [84].

210 Exhibit 25-12, ‘Statement of Jody Ann Barney’, 11 June 2022, at [45]; Exhibit 25-19, ‘Joint statement of Kunmanara (Margaret) Smith and Kim McRae’, 21 June 2022, at [125].

211 Exhibit 25-84, ‘Statement of Patricia Turner’, 27 June 2022, at [118–19].

212 Exhibit 25-78, ‘Joint statement of Jenny Bedford and Cassie Atchison’, 17 June 2022, at [72].

213 Transcript, Jenny Bedford, Public hearing 25, 14 July 2022, P-308 [4–16].

214 Transcript, Jenny Bedford, Public hearing 25, 14 July 2022, P-308 [18–20].

215 Submissions by the Australian Government in response to Counsel Assisting’s submissions in Public hearing 25, 14 December 2022, SUBM.0042.0001.0001, p 22 [83].

216 Transcript, Scott McNaughton, Public hearing 25, 15 July 2022, P-399 [37–41], P-400 [31–34].

217 Transcript, Scott McNaughton, Public hearing 25, 15 July 2022, P-399 [6–9].

218 Transcript, Scott McNaughton, Public hearing 25, 15 July 2022, P-399 [10–12].

219 Submissions by the Australian Government in response to Counsel Assisting’s submissions in Public hearing 25, 14 December 2022, SUBM.0042.0001.0001, p 22 [83].

220 Exhibit 25-63, TRA.3000.0013.0021, P-6 [26–38]; Exhibit 25-43, TRA.3000.0013.0047, P-7 [18–38]; Exhibit 25-64, ‘Joint statement of Emily Carter and Dr Lauren Rice’, 20 June 2022, at [34]; Exhibit 25-46, ‘Statement of Stella (Topsy) Jackamarra’, 22 June 2022, at [126]; Exhibit 25-1, ‘Statement of ‘Daisy’’, 21 June 2022, at [12]; Exhibit 25-34, ‘Statement of Joanne Houghton’, 21 June 2022, at [112].

221 Exhibit 25-64, ‘Joint Statement of Emily Carter and Dr Lauren Rice’, 20 June 2022, at [34(a)–(b), (d)]; Exhibit 25-34, ‘Statement of Joanne Houghton’, 21 June 2022, at [112]; Exhibit 25-46, ‘Statement of Stella (Topsy) Jackamarra’, 22 June 2022, at [126].

222 Exhibit 25-41, 'Statement of Geoff Davis', 15 June 2022 at [48]; Exhibit 25-23, 'Statement of Beth Walker', 1 June 2022, at [69]; Transcript, 'Joan', Public hearing 25, 11 July 2022, P-49 [38–46].

223 See, for example, Exhibit 25-23, 'Statement of Beth Walker', 1 June 2022, at [63].

224 Exhibit 25-41, 'Statement of Geoff Davis', 15 June 2022, at [48].

225 Exhibit 25-23, 'Statement of Beth Walker', 1 June 2022, at [72], [159].

226 Transcript, Scott McNaughton, Public hearing 25, 15 July 2022, P-391 [8–13].

227 Transcript, Scott McNaughton, Public hearing 25, 14 July 2022, P-391 [22–25].

228 Transcript, Bakoi Namok, Public hearing 25, 12 July 2022, P-170 [13–18]; Exhibit 25-43, TRA.3000.0013.0047, P-7 [6–9]; Exhibit 25-63, TRA.3000.0013.0021, P-13 [34–37].

229 Exhibit 25-43, TRA.3000.0013.0047, at P-5 [39–43].

230 Exhibit 17-32.12, CTD.9999.0049.0001, p 2 [5–6].

231 Exhibit 25-95, 'Statement of Scott McNaughton', 15 June 2022, at [118].

232 Exhibit 25-86, EXP.0029.0004.0001, p 14 (Recommendation 7).

233 Transcript, Scott McNaughton, Public hearing 25, 14 July 2022, P-331 [46–47] – P-332 [1–3].

234 Exhibit 25-92, 'Statement of Damian Griffis and June Riemer', 23 June 2022, at [79]; Transcript, Damian Griffis, Public hearing 25, 14 July 2022, P-270 [9–12].

235 Exhibit 25-92, 'Statement of Damian Griffis and June Riemer', 23 June 2022, at [26]; Transcript, Damian Griffis, Public hearing 25, 14 July 2022, P-272 [15–20], [45–47].

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252 Exhibit 25-92, 'Statement of Damian Griffis and June Riemer', 23 June 2022, at [29], [40–41]; Exhibit 2534, 'Statement of Joanne Houghton', 21 June 2022, at [72], [78]; Exhibit 25-12, 'Statement of Jody Ann Barney', 11 June 2022, at [23]; Exhibit 25-23, 'Statement of Beth Walker', 1 June 2022, at [46]; Exhibit 2519, 'Joint statement of Kunmanara (Margaret) Smith and Kim McRae', 21 June 2022, at [100], [120], [157]; Exhibit 25-8, 'Statement of 'Joan'', 22 June 2022, at [84].

253 Exhibit 25-023, 'Statement of Beth Walker', 1 June 2022', [83–84]; Exhibit 25-92, 'Statement of Damian Griffis and June Riemer', 23 June 2022, at [40]; Exhibit 25-34, 'Statement of Joanne Houghton', 21 June 2022, at [72], [111]; Exhibit 25-84, 'Statement of Patricia Turner', 27 June 2022, at [79].

254 Exhibit 25-84, 'Statement of Patricia Turner', 27 June 2022, at [79]; Exhibit 25-12, 'Statement of Jody Ann Barney', 11 June 2022, at [23]; Exhibit 25-1, 'Statement of 'Daisy'', 21 June 2022, at [56]; Exhibit 2534, 'Statement of Joanne Houghton', 21 June 2022, at [78], [110]; Exhibit 25-33, 'Statement of Bakoi Namok', 9 July 2022, at [50].

255 Exhibit 25-12, ‘Statement of Jody Ann Barney’, 11 June 2022, at [22–23].

256 Exhibit 25-23, ‘Statement of Beth Walker’, 1 June 2022, at [47–49].

257 Transcript, Beth Walker, Public hearing 25, 12 July 2022, P-107 [31–34]. See also Exhibit 25-34, ‘Statement of Joanne Houghton’, 21 June 2022, at P-46 [1–12].

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261 Submissions by the Australian Government in response to Counsel Assisting’s submissions in Public hearing 25, 14 December 2022, SUBM.0042.0001.0001, p 10 [32]. See also Transcript, Scott McNaughton, Public hearing 25, 15 July 2022, p 387 [22–40].

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263 Submissions by the Australian Government in response to Counsel Assisting’s submissions in Public hearing 25, 14 December 2022, SUBM.0042.0001.0001, p 10 [34].

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266 Exhibit 25-19, ‘Joint statement of Kunmanara (Margaret) Smith and Kim McRae’, 21 June 2022, at [79]; Exhibit 25-23, ‘Statement of Beth Walker’, 1 June 2022, at [17].

267 Exhibit 25-19, ‘Joint statement of Kunmanara (Margaret) Smith and Kim McRae’, 21 June 2022, at [79].

268 Exhibit 25-46, ‘Statement of Stella (Topsy) Jackamarra’, 22 June 2022, at [135].

269 Exhibit 25-21, NPY.0001.0001.0001, p 10; see also Exhibit 25-1, ‘Statement of ‘Daisy’, 21 June 2022, at [44]; Exhibit 25-46, ‘Statement of Stella (Topsy) Jackamarra’, 22 June 2022, at [112–17]; Exhibit 25-43, TRA.3000.0013.0047, P-9 [8–17].

270 Exhibit 25-41, ‘Statement of Geoff Davis’, 15 June 2022, at [39].

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273 Exhibit 25-19, ‘Joint statement of Kunmanara (Margaret) Smith and Kim McRae’, 21 June 2022, at [71], [81].

274 Exhibit 25-19, ‘Joint statement of Kunmanara (Margaret) Smith and Kim McRae’, 21 June 2022, at [71], [81].

275 Exhibit 25-34, ‘Statement of Joanne Houghton’, 21 June 2022, at P-47 [27–32]; Exhibit 25-19, ‘Joint Statement of Kunmanara (Margaret) Smith and Kim McRae’, 21 June 2022, at [80–82]; Exhibit 25-41, ‘Statement of Geoff Davis’, 15 June 2022, at [39].

276 Exhibit 5.167, DRC.2000.0002.0747, 18 July 2019, at [11.1].

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283 Submissions by the Australian Government in response to Counsel Assisting’s submissions in Public hearing 25, 14 December 2022, SUBM.0042.0001.0001, p 16 [60].

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287 Exhibit 25-19, ‘Joint statement of Kunmanara (Margaret) Smith and Kim McRae’, 21 June 2022, at [79–82]; Exhibit 25-41, ‘Statement of Geoff Davis’, 15 June 2022, at [36–40], [42].

8. The case for structural reform

Key points

- Policy frameworks and service delivery often fail to respond to the distinct needs of First Nations people with disability. Government policy-making and funding do not address the ‘double disadvantage’ experienced by First Nations people with disability. Agencies and departments often operate in ‘silos’, unaware of the actions and approaches of each other.
- As a consequence, the needs of First Nations people with disability are often overlooked, ignored or forgotten.
- The voices of First Nations people with disability need to be strengthened. A First Nations Disability Forum would improve policy responses for First Nations people with disability and enhance access to culturally safe services.
- The Disability Sector Strengthening Plan attempts to align the complex policy landscape. However, governments should provide clear commitments to funding and timeframes to drive implementation and achieve outcomes, with stronger reporting requirements.
- Cultural safety is essential to service provision for First Nations people with disability and prevention of violence, abuse, neglect and exploitation. Investing in the community-controlled sector and local workforces will improve provision of culturally safe, local services to First Nations people with disability.
- First Nations people are under-represented in disability and care workforces. This may contribute to culturally unsafe disability service provision.
- There is an urgent need to invest in the First Nations disability workforce to address current service gaps. This includes building the disability literacy of the existing workforce and expanding the workforce in the long term.
- A First Nations Disability Fund should be established to build disability expertise into existing community-controlled organisations.
- Non-Indigenous providers have an important ongoing role in disability service delivery. They must also provide cultural safety. This can be achieved through the development of cultural safety standards, and the introduction of locally grounded, disability-specific cultural safety training requirements.

8.1. Introduction

Aboriginal and Torres Strait Islander people with disabilities, they walk in multiple worlds, being the Aboriginal and Torres Strait Islander world, the disability community and the rest of the community, yet there is no meaningful way for their intersectional rights to be upheld.[1]

Our terms of reference acknowledge a person with disability's experiences of violence, abuse, neglect and exploitation are often multi-layered.[2] For this reason, they direct us to have particular regard to the situation of First Nations people with disability.[3]

At present, policy frameworks and service delivery often fail to recognise and respond to the distinct needs of First Nations people with disability. Their particular experiences are often overlooked or ignored in data collection and reporting. During a number of our public hearings, witnesses described how the invisibility of First Nations people with disability has resulted in systemic neglect and lack of accountability.

Policy and practice across different service systems need to take better account of the discrimination and disadvantage experienced by First Nations people with disability. A fractured approach across service systems results in a lack of coordination and gaps in responsibility.

At Public hearing 4, 'Health care and services for people with cognitive disability', Dr Scott Avery described the 'circular reference of avoidance' occurring between different plans and strategies responsible for the health of Aboriginal people with disability:[4]

> So the Aboriginal Health Plan says, 'We will improve the health of Aboriginal people with disability through the National Disability Strategy'. So you go to the National Disability Strategy and it says, 'We will delegate responsibility for the health of Aboriginal people to the Australian Government for improving health outcomes for Aboriginal people with disability'. So you go to that document, and it says, 'We will improve the health of Aboriginal people with disability through Close the Gap and the Health Plan'.[5]

This chapter makes recommendations to strengthen the voices of First Nations people with disability to address these gaps. It first outlines the gaps and 'silos' in existing strategies, before examining the barriers to accessing equitable supports and the underinvestment in culturally safe and appropriate services.

We make a number of recommendations, including:

- creating a National First Nations Disability Forum to drive policy and service reform
- strengthening the Disability Sector Strengthening Plan (DSSP)
- setting cultural safety standards in disability service delivery
- investment in the First Nations disability workforce
- funding for First Nations Community Controlled Organisations for the provision of disability supports.

8.2. The existing First Nations disability policy landscape

> Each of these systems takes a top-down approach which does not correlate to Aboriginal and Torres Strait Islander community business. These systems are based in settler colonialism ideas and structures, and implemented without any consideration for how they would work for our community.[6]

First Nations disability policy is a changing landscape. This section looks at recent developments across:

- Australia's Disability Strategy 2021-2031 (ADS)
- the National Agreement on Closing the Gap
- the implementation strategies for the National Disability Insurance Scheme (NDIS).

Australia's Disability Strategy

The ADS is Australia's national policy framework on disability. It follows on from the National Disability Strategy (NDS), which ran from 2009 to 2020. The NDS was the first time all levels of government 'committed to a unified, national approach to improving the lives of people with disability, their families and carers, and to providing leadership for a community-wide shift in attitudes'.[7] The vision of the NDS was for 'an inclusive Australian society that enables people with disability to fulfil their potential as equal citizens'.[8] It recognised that all governments, non-government organisations, businesses and the wider community have a role to play in achieving this vision.[9]

Despite the introduction of a national policy framework, the NDS did not lead to better outcomes for many people with disability. This was also the case for many First Nations people with disability. While the NDS identified 'Aboriginal and Torres Strait Islander people with disability are among the most disadvantaged members of the Australian community', it did not translate meaningfully into the policy directions, outcomes or areas for action.[10]

The ADS similarly acknowledges the importance of an intersectional approach. For example, it refers to the increased risks of violence and imprisonment experienced by First Nations women with disability.[11] However, the outcome areas and targeted action plans intended to drive implementation again do not reflect the priorities, needs and experiences of First Nations people with disability.

Volume 5, *Governing for inclusion*, describes the lack of improved outcomes under the NDS in more detail, and recommends the Australian Government review national agreements and strategies to ensure they better align with the ADS. The Australian Government should ensure that the particular situation of First Nations people with disability are considered in that review.

National Agreement on Closing the Gap

The National Agreement on Closing the Gap was agreed in July 2020, following nearly two decades of the campaign to Close the Gap and the National Indigenous Reform Agreement from 2008.

The 2008 Closing the Gap on Indigenous Disadvantage framework was criticised for excluding disability. Dr Avery has identified how the framework lacked a standalone target to address disability-related outcomes, 'despite the impact of disability in attaining other Closing the Gap indicators'.[12] Rather, disability was a secondary priority, without dedicated funding, governance or accountability.[13]

At Public hearing 4, Dr Avery described how the First Peoples Disability Network (FPDN) advocated for the inclusion of disability in Closing the Gap strategies. He told us that despite this, disability had been 'actively dis-acknowledged'.[14] Mr Griffis, FPDN CEO, and Ms Riemer, FPDN Deputy CEO, said disability was 'not adequately accommodated in Closing the Gap strategies' and that this was a 'critical oversight'.[15] FPDN previously recommended the Closing the Gap framework be linked to the NDS to enable better coordinated policy and programs across governments, established in partnership with First Nations people with disability and their organisations.[16]

The National Agreement focuses on strengthening the partnership approach between First Nations organisations and governments. The intent is to allow for community-led solutions and services to meet the needs of First Nations people. The National Agreement similarly acknowledges the diversity that exists within First Nations communities and the higher rate of disability among First Nations communities. However, in 2022, Mr Griffis and Ms Riemer from FPDN raised concerns that strategies under the National Agreement did not adequately include disability.[17]

Ms Turner AM, CEO of NACCHO, said that while disability is ‘a key focus’ of the National Agreement:

> Stronger evidence is required on the prevalence of disability and the impact of disability on Aboriginal and Torres Strait Islander people and communities. Given this is currently a notable gap, this is where future policy and programs can have significant impact.[18]

The Disability Sector Strengthening Plan

On 26 August 2022, the Coalition of Aboriginal and Torres Strait Islander Peak Organisations and all Australian governments agreed in principle to the Disability Sector Strengthening Plan (DSSP).[19] The DSSP was co-designed by the Department of Social Services (DSS) and FPDN.[20]

The DSS describes the DSSP as a key commitment under the National Agreement’s *Priority Reform Two: build the community-controlled sector*.[21] The DSSP’s overall objectives are to strengthen the community-controlled disability sector and improve outcomes for First Nations people with disability.[22] However, it does not commit any party to resources or actions ‘not already announced’, but is instead ‘offered as a resource to be used over the next three years to prioritise, partner and negotiate beneficial sector-strengthening strategies’.[23]

NDIA First Nations Advisory Council

Chapter 7 outlined the challenges for First Nations people in participating in the NDIS, and accessing services and supports, particularly for remote communities.

In late February 2023, the NDIA announced a partnership with FPDN and a new First Nations Advisory Council (FNAC).[24] In a draft letter it provided to the Royal Commission, the NDIA describes the purpose of this Advisory Council as providing First Nations-led advice on how it can improve outcomes for First Nations people with disability.[25] Initially, this will involve a process of understanding the challenges facing First Nations peoples accessing and using the NDIS.

The Royal Commission has provided an opportunity to bear witness to many stories of First Nations people with disability, and the challenges they experience in accessing culturally safe and appropriate services and supports through the NDIS. We encourage the Advisory Council to consider the stories First Nations people have told us when starting to build its understanding of the challenges and barriers faced by First Nations people with disability in participating in the NDIS.

The primary purpose of the partnership between the NDIA and FPDN is to develop the NDIA's First Nations Strategy and corresponding Action Plan.[26] In the draft letter, the NDIA also said the Advisory Council will guide development of its First Nations Strategy.[27] The NDIA has indicated that it intends to align the First Nations strategy with the National Agreement. We encourage the Advisory Council to consider the broader policy landscape, beyond the Closing the Gap National Agreement and the DSSP, when developing its First Nations Strategy.

An issue raised by witnesses at our public hearings was the lack of focus on First Nations disability in national policy frameworks.[28] The Victorian Aboriginal Community Controlled Health Organisation (VACCHO) suggested community control is key to achieving greater alignment between Closing the Gap, the NDIS and the ADS.[29]

Beyond the disjointed nature of policy frameworks, we also heard how different agencies and departments operated within silos, unaware of the data, information, actions and approaches of another.[30] As a consequence, the needs of First Nations people with disability are often overlooked, ignored or forgotten.

However, we believe there is an opportunity to build on recent developments. While there is evidence that greater consideration of First Nations disability is occurring, there is still much that can be done to ensure a more integrated approach to realise better outcomes for First Nations people with disability. Our recommendations to address this are below.

8.3. Elevating First Nations disability policy

A First Nations Disability Forum

We believe the voices of First Nations people with disability need to be strengthened and elevated to prevent these omissions occurring in the future. We have gathered evidence that demonstrates the community-controlled sector has a safeguarding role in relation to the occurrence of violence against, and abuse, neglect and exploitation of, First Nations people with disability.

We recommend the Australian Government and state and territory governments support the establishment of a First Nations Disability Forum. The purpose of the forum would be to address the lack of direct diverse voices of, and policy responses to, First Nations people with disability across key areas funded by the Australian and state and territory governments. It should also enhance access to culturally safe services and supports for First Nations people with disability.

The forum would create a platform for existing First Nations community-controlled sector organisations to collaborate including with First Nations people with disability. As a community-led mechanism, it would drive public policy and service reform from the ground up, ensuring culturally safe and appropriate responses for First Nations people with disability. This is an effective and economical approach to policy and service reform.

The forum should provide an opportunity to combine the policy expertise of FPDN with the service system expertise of the First Nations community-controlled sector and on-the-ground experiences of policy and services from members of the First Nations community with disability. Together, they should work with the government parties that are signatories to the National Agreement.

The forum should:

- provide a mechanism for First Nations people with disability to provide input into policy, programs and practices, directly and through community-controlled advocacy and service providers
- provide a platform for existing community-controlled organisations to collaborate across relevant strategies and frameworks and provide leadership and expertise on the issues that First Nations people with disability face
- advocate for the inclusion of First Nations disability policy in relevant national agreements, strategies and plans
- establish initiatives to prevent and eliminate the violence, abuse, neglect and exploitation that First Nations people with disability experience
- improve the interaction and coordination between different agencies, departments and systems to improve system navigation for First Nations people with disability
- work alongside governments to address the systemic neglect of First Nations people with disability by ensuring appropriate public policy responses
- oversee implementation of our recommendations relevant to First Nations people with disability.

Government support for the forum will be critical. We have heard how the community-controlled sector is already stretched. This initiative must have the resources to coordinate and support its members effectively, to ensure that it can provide valuable guidance on how to identify and address priority areas. The First Nations Disability Forum will enable community-led policy development and enhance access to culturally safe disability services and supports.

It should be supported by a First Nations Disability fund, with the purpose of:

- supporting the operation of, and participation in, the forum
- implementing the DSSP
- developing the First Nations disability workforce.

We note the DSSP Working Group ceased operating after the in-principle agreement of the DSSP.[31] We also note the recent announcement of the NDIA First Nations Advisory Council. We recognise there may be significant overlap in the membership of the Advisory Council and the proposed First Nations Disability Forum. We suggest the forum should work collaboratively across relevant strategies and frameworks to provide leadership and oversight of strategic priorities. It should strengthen and reinforce existing community-controlled organisations under the auspices of the FPDN, as the peak body for First Nations people with disability.

Recommendation 9.10 First Nations Disability Forum

The Australian Government and state and territory governments should support the establishment of a First Nations Disability Forum to lead further development and implementation of the Disability Sector Strengthening Plan (DSSP) by the end of March 2024. The Forum should consist of representatives of:

- First Peoples Disability Network
- First Nations Community Controlled Organisations
- both Aboriginal and Torres Strait Islander peak bodies
- First Nations people with disability.

The Forum should be supported by a First Nations disability investment fund, with the purpose of:

- supporting the operation of, and participation in, the Forum
- implementing the DSSP
- developing the First Nations Disability Workforce.

The Forum should have the capacity to direct funding under the DSSP to:

- enable First Nations people with disability to provide advice and guidance from their lived experience to the Forum
- enable community-controlled organisations to develop their capacity to design and deliver disability-specific services and supports
- enable community-controlled organisations to work with other organisations to drive national leadership in disability policy and services reform
- enable community-controlled organisations to deliver on specific priority areas as identified in the DSSP
- enable the participation of community-controlled organisations not engaged in the Coalition of Aboriginal Peaks process
- support First Nations community-based organisations across the health, criminal justice and early childhood sectors to improve workforce disability competency to ensure First Nations people with disability receive appropriate disability support
- take into consideration the recommendations of the Royal Commission.

The Forum should develop and implement a strategy, supported by the First Nations disability investment fund, to build disability-specific expertise into First Nations Community Controlled Organisations.

Building on the Disability Sector Strengthening Plan

The in-principle agreement of the DSSP is an important step forward. It attempts to align the complex policy landscape for First Nations disability. It is responsive to the need for better coordination across the National Agreement and the ADS:

> The Disability SSP serves as a key linking document that provides a framework to align the key priorities of the Strategy and the National Agreement … The endorsement of both the National Agreement and the Strategy by all levels of government in the past two years presents a unique opportunity to drive national action and improve outcomes with and for First Nations people with disability.[32]

While the DSSP is an important step in advancing the rights of First Nations people with disability, we believe there are a number of ways the DSSP could be strengthened. At present, it does not commit any party to resources or actions 'not already announced' but is framed as a resource to assist with prioritisation, partnership and negotiation.[33] It runs only until 2025.

We suggest the DSSP could include:

- agreed priority areas to improve coordination, linked to agreed timeframes to assist in driving implementation and achieving outcomes
- a commitment to future funding and longer timeframes to ensure progress is sustainable, including for the FPDN as the peak body for First Nations disability
- agreed timeframes for delivering actions and achieving outcomes to assist driving implementation
- annual reporting requirements for government parties to improve transparency and accountability.

It would be appropriate for the priority areas to be determined through consultation with the First Nations community-controlled sector, potentially through the First Nations Disability Forum. However, we note the compelling evidence and information we have received on the experiences of First Nations families with disability, including parents and children with disability. These issues intersect across education, health, child protection and criminal justice. We suggest these issues are considered as potential priority areas for the DSSP.

We propose that all governments should provide clearer commitments to funding and agreed timeframes in order to drive implementation and achieve outcomes. We also believe that the reporting requirements for government parties should be strengthened. The current DSSP suggests parties 'may' report on progress in annual implementation plans. Making such reporting mandatory would improve accountability. Each government party should provide a disability-specific report card on an annual basis to ensure transparency and visibility.

Recommendation 9.11 Building on the Disability Sector Strengthening Plan

Parties to the National Agreement on Closing the Gap should commit to releasing a revised Disability Sector Strengthening Plan (DSSP) in partnership with the First Nations Disability Forum by the end September of 2024. The revised DSSP should have:

- agreed priority areas, determined through consultation with the community-controlled sector under the guidance of First People's Disability Network
- a commitment to future funding and longer timeframes
- agreed timeframes for delivering actions and achieving outcomes
- annual reporting requirements for government parties to the National Agreement on Closing the Gap.

These recommendations aim to enable a First Nations community-led response to address policy gaps and silos, improve culturally safe and appropriate service delivery, and increase access to services and support for rural and remote First Nations communities.

8.4. Ensuring culturally safe and responsive services

The Royal Commission has consistently heard about the need to invest in the development of culturally appropriate and safe disability services for First Nations people. This can be achieved by developing workforce capacity in First Nations organisations and cultural safety standards for non-First Nations organisations.[34] These matters have been reiterated in evidence provided to the Royal Commission in Public hearing 4, Public hearing 8, 'The experiences of First Nations people with disability and their families in contact with child protection systems', Public hearing 16, 'First Nations children with disability in out-of-home care', Public hearing 11, 'The experiences of people with cognitive disability in the criminal justice system', Public hearing 17, 'The experience of women and girls with disability with a particular focus on family, domestic and sexual violence', and Public hearing 25, 'The operation of the NDIS for First Nations people with disability in remote and very remote communities'.

The First Nations community-controlled sector has told the Royal Commission that this investment must be long term. It must occur structurally in terms of the policy frameworks underlying the disability service sector. Key policy frameworks such as the Australian Disability Strategy and Closing the Gap National Agreement, must have a stronger and more coordinated focus on the distinct needs of First Nations people with disability.

Improving the cultural safety of services

As discussed in Chapter 3, cultural safety is essential to the proper provision of services to First Nations people with disability and the prevention of violence, abuse, neglect and exploitation. Improving cultural safety for First Nations people with disability can occur through increasing support for community-controlled organisations to provide services and through increasing cultural safety in mainstream service providers.

Policy frameworks for supporting enhanced cultural safety

Despite the existence of numerous frameworks aimed at improving the lives and wellbeing of all First Nations people, a lack of cultural safety and appropriateness continues to be an issue. As described in Chapter 7, there is a need for reform to ensure First Nations people with disability can access culturally safe NDIS services.

Several national policy frameworks are critical to supporting the cultural safety of First Nations people with disability in Australia. These include the National Agreement, Australia's Disability Strategy and the National Aboriginal and Torres Strait Islander Health Plan 2013–2023.

The importance of cultural respect and cultural safety is also outlined in Australian Government documents such as the:

- Cultural Respect Framework 2016–26 for Aboriginal and Torres Strait Islander Health
- National Aboriginal and Torres Strait Islander Health Plan 2021–2031.

Cultural safety and eliminating racism have recently been included as transformation elements within the National Agreement. These priority reform areas identify the need to address institutional racism, discrimination and unconscious bias, and to embed cultural safety within government mainstream institutions and agencies.[35]

Evidence presented to this inquiry described the current policy landscape as poorly designed, without First Nations input, which renders invisible those with disability.[36] The abolition of First Nations representative bodies has resulted in an absence of First Nations input into national policy decision-making. As a consequence, self-determination, cultural safety and strategies to address intersectional discrimination have not been at the forefront of national policies and plans, and disability has either been absent or inadequately reflected.[37] Developing cultural safety standards is an important component of improving the competency of non-Indigenous disability organisations and their ability to deliver culturally appropriate services, and administering any diagnostic tools. All organisations, and particularly NDIS service providers, have a responsibility to comply with cultural safety standards when delivering services to First Nations people with disability. These standards may have utility outside the context of the NDIS, at Commonwealth and state or territory levels.

There have been numerous opportunities to enhance cultural safety within mainstream service delivery contexts. These have focused on the development of agreed cultural safety standards; mandatory training for NDIS service providers, including NDIA staff; and enhanced reporting requirements against major frameworks such as the ADS and the National Agreement.

Many organisations have stressed the importance of improving the cultural safety of non-Indigenous providers through the introduction of cultural safety training requirements that can be locally grounded and specific to the disability sector.[38] This is particularly the case given the number of non-First Nations disability service providers, compared to First Nations disability service providers.

The Royal Commission has heard a commitment to cultural safety must be robust and based on genuine engagement with First Nations people and their culture. It should not be a 'box ticking' exercise.[39] On that basis, cultural safety must not just be about undertaking one-off training, but a commitment to fundamental shifts within organisational cultures and mindsets.[40] So far, proposals for change concerning cultural safety have primarily focused on the NDIA ensuring that minimum standards are met when delivering services to First Nations people with disability.

Recommendation 9.12 Disability-inclusive cultural safety standards

The Australian Government in partnership with the First Nations Disability Forum should develop disability-inclusive cultural safety standards for the provision of services for First Nations people with disability.

Disability service providers that support and have a responsibility for First Nations people with disability, including in the health, criminal justice and early childhood sectors, should incorporate these disability-inclusive cultural safety standards in their practices and organisations.

The NDIA should implement the cultural safety standards to improve its own cultural competency. This should be achieved through improved training for NDIA staff, particularly around the need for interpreters and language translators.

8.5. Improving disability services for First Nations people

First Nations people with disability encounter numerous barriers to accessing culturally safe and appropriate disability services and supports. These barriers range from a lack of cultural safety and the scarcity of appropriate disability services and supports, particularly in remote regions, to the obstacles that prevent First Nations people with disability having equitable access to services across systems such as health and education.

Our understanding of these barriers is informed by the ongoing and interlinked impacts of colonisation, intergenerational trauma, racism and social disadvantage. These contextual influences are not merely conceptual for First Nations people with disability. They punctuate the experiences of First Nations people with disability throughout their lives.

Disability support from First Nations community-led organisations

In Public hearing 27, we heard evidence about the importance of First Nations people leading, designing and implementing processes and programs for First Nations people with disability in contact with the justice system.[41] First Nations witnesses and organisations gave evidence about their work in delivering culturally safe supports and services that help First Nations people in custody and when transitioning back into the community.

At Public hearing 11, Ms Cheryl Axleby, CEO of the Aboriginal Legal Rights Movement in Australia, explained that services and supports for First Nations people with disability must be underpinned by the principles of self-determination and co-design with affected communities.[42] She said this requires:

> A commitment to centring the experiences of Aboriginal and Torres Strait Islander people with disability, especially those with the criminal justice system, through ensuring that all services, programs, procedures and practices are co-designed, co-delivered, and evaluated by and with meaningful involvement from people with disability.[43]

Central to this approach is to have First Nations community-based organisations providing culturally safe supports to First Nations prisoners in custody and to facilitate connection to family, Country and culture.[44] Ms Axleby identified the need to create positions for 'disability support workers' to assist First Nations people with disability in contact with the criminal justice system.[45] Ms Axleby said in the view of NATSILS, only ACCOs can be truly culturally safe, as they are connected to community and families, and understand cultural nuances and lived experiences.[46] Ms Axleby recommended:

> more specialised disability support co-located within the ATSILS to fully support First Nations people with disability to meet their needs while they are dealing with the criminal justice system.[47]

Culturally safe mainstream services

Chapter 7 describes the ways in which First Nations people with disability struggle to access services and supports through the NDIS. It discusses the critical role played by First Nations Community Controlled Organisations in providing culturally safe and appropriate services, particularly in rural and remote communities.

However, First Nations people with disability have told us about gaps in service provision across sectors, not just in relation to the operation of the NDIS.[48] These gaps can result in First Nations people with disability having to make a choice between supports that are either disability-safe or culturally safe. In some places, there is no service available at all.

National Disability Services acknowledged the 'complex ways' disability services interact with other service systems, and the need for increased policy coherence.[49]

The Kimberley Stolen Generation Aboriginal Corporation described the 'lack of cohesion' between service providers, and how First Nations people with disability felt 'isolated, neglected, abused and ignored', resulting in them withdrawing from seeking help.[50] They proposed the way to improve the situation is 'by working together more cohesively', with government funding being directed toward existing local services.[51]

The Victorian Aboriginal Community Controlled Health Organisation (VACCHO) said First Nations people ‘are more likely to seek health and community services from a provider that offers cultural safety’.[52] Conversely, they said Aboriginal people may delay or avoid seeking services, ‘largely due to the discrimination faced by Aboriginal people with disability in healthcare settings’.[53]

Danila Dilba Health Service outlined the fragmented nature of supports available to First Nations communities, particularly First Nations children with disability.[54] It similarly said government departments were unclear on their respective responsibilities when First Nations children with disability are placed in out-of-home care or juvenile detention, and that the ‘high degree of fragmentation in the coordination of assessment’ was a barrier for children accessing support in those systems.[55]

The Victorian Aboriginal Child Care Agency (VACCA) described the vulnerability of First Nations children with disability entering and exiting the out-of-home care system. They raised concerns about the ‘siloed relationship’ between the disability and child welfare sectors, which affects the co-ordination, access and availability of supports.[56] They said the lack of Aboriginal-specific services and supports for Aboriginal children and young people with disability in Victoria made it impossible for ‘Aboriginal children and their parents/carers to exercise their right to self-determination and choice’.[57]

8.6. Growing the First Nations disability workforce

In several public hearings, representatives from First Nations peak organisations identified the need for investment in the First Nations disability workforce. Public hearing 25, which focused on the operation of the NDIS in remote and very remote communities, particularly heard about this issue, but it also applies to disability supports and services more generally.[58]

The CEO of a First Nations Community Controlled Organisation told us during a workshop that of the 500 staff in her sector of child and community welfare, very few had any disability training.[59] She described the lack of training and resources to upskill staff in disability, despite the introduction of the NDIS. She believed this was a missed opportunity because of the resource that community-controlled organisations are to First Nations people.[60]

In response to *The experience of First Nations people with disability in Australia issues paper,* VACCA said:

> ACCOS require training to build knowledge and expertise in the disability sector including how to effectively navigate the NDIS. In doing so, staff will be able to support and empower young people and their carers and/or parents to utilise the system … This in and of itself, is self-determination of what knowledge base informs and best supports the needs of Aboriginal children, families and community.[61]

Witnesses at Public hearing 16 also identified the opportunity to uplift the disability workforce, with benefits for people accessing services as well as the First Nations workforce. Ms Catherine Liddle, CEO of SNAICC, said there was:

> a lot of work to be done in the short term in building the skill sets of the existing workforce, but in the long term, expanding that workforce to ensure that our mob are able to actually work in these roles and deliver the services themselves.[62]

During Public hearing 17, Ms Thelma Schwartz, Principal Legal Officer at the Queensland Indigenous Family Violence Legal Service, identified the lack of disability-specific services for First Nations women and girls, particularly in regional, rural and remote areas.[63] She recognised the importance of the model of care provided by local First Nations organisations over fly-in-fly-out services.[64] Ms Schwartz acknowledged the lack of disability specific expertise within existing organisations and the need for investment in community-controlled models beyond legal support.[65]

The current scope of the First Nations disability workforce

We commissioned research on options available to improve service availability and accessibility for First Nations people with disability. The research defined the First Nations disability workforce as any worker who services First Nations people with disability, regardless of employer or cultural identity.[66] However, it also considered the proportion of people within that workforce who identify as First Nations themselves.[67] The analysis suggests First Nations people are under-represented in the disability workforce nationally, and this may ‘contribute to culturally unsafe disability service provision’.[68]

An analysis of data from the Australian Bureau of Statistics shows a substantial disparity in the proportion of First Nations people employed across sectors and geographic locations. A much higher proportion of Indigenous health workers identify as Aboriginal or Torres Strait Islander or both, compared to aged and disability carers, and welfare support workers.[69] The data also suggests a higher proportion of First Nations disability care workers employed in remote and very remote locations.[70]

The research report makes a number of observations about workforce challenges for First Nations disability service provision:[71]

- The disability sector needs more workers generally but particularly in remote and very remote areas.
- First Nations people will benefit from greater representation in all care sector occupations.
- Cultural competency must be embedded in service provision to ensure culturally safe support, both in major cities where First Nations representation is very low, and in remote and very remote areas where capacity is needed but may not come from First Nations workers.

DSSP actions for a First Nations disability workforce

Priority Reform Two of the National Agreement on Closing the Gap is building the community-controlled sector. Under its auspices, the Coalition of Aboriginal and Torres Strait Islander Peak Organisations and all Australian governments agreed to the Disability Sector Strengthening Plan (DSSP).

The DSSP recognises that ‘a dedicated and identified Aboriginal and Torres Strait Islander workforce’ is an element of a strong sector, as outlined in the National Agreement.[72] A number of witnesses have identified this as impetus for building the community-controlled disability sector.[73]

The DSSP identifies that the current workforce data is not comprehensive, what it suggests is that overall the First Nation disability workforce is ‘either emerging or limited’.[74] It also notes that existing employment and workforce strategies at national or state and territory level do not focus on the community-controlled disability workforce.[75]

The DSSP contains a number of actions and outcomes intended to strengthen a dedicated First Nations disability workforce for the community-controlled disability sector, with the capacity and capability to deliver culturally safe, accessible and inclusive services informed by knowledge of disability rights.[76]

We believe investment in the First Nations disability workforce must occur through the DSSP, so that it can be monitored as part of the National Agreement reporting process. Sustained commitment is needed to grow a competent First Nations disability workforce. These arrangements should be negotiated through the First Nations Disability Forum to deliver the actions and outcomes identified by the DSSP.

Funding a First Nations disability workforce

First Nations Community Controlled Organisations represent the core of the existing First Nations disability workforce. At present, however, they have varying levels of capacity and readiness to provide disability services and supports. Nonetheless they are increasingly taking on more responsibility for service delivery. We heard that these organisations often ‘plug the gap’ for disability service provision, but often without appropriate investment or funding.[77] In some instances, this may risk the viability of otherwise sustainable organisations, particularly where they are required to operate in deficit.[78]

During Public hearing 25, Ms Cassie Atchison, CEO of Broome Regional Aboriginal Medical Services, said her organisation provided NDIS disability supports to First Nations people, but had to subsidise the program from its own operating costs.[79] Ms Patricia Turner AM, CEO of NACCHO, said First Nations health sector organisations could not continue to subsidise the NDIS to enable it to reach First Nations people with disability. Ms Turner AM identified the need for better funding arrangements and an agreement with the NDIA to facilitate engagement with First Nations communities.[80]

Given their role, geographic distribution and the trust they enjoy within communities, First Nations Community Controlled Organisations provide an important avenue to improve the availability of culturally appropriate disability services and supports. Investment in a First Nations disability workforce is key to addressing current service gaps. Witnesses highlighted the diversity, strength, and geographic distribution of the existing First Nations community-controlled sector, as a platform from which this workforce can be built.

The research report on options to improve service availability and accessibility for First Nations people with disability, estimates an additional 13,000 First Nations workers are needed to provide supports between 2022 and 2031.[81] This includes home care, community care and allied health services that support people with disability through the NDIS. This is an approximate estimate, based on the total workforce assumption consistent with First Nations participants and overall estimates of the disability support workforce and NDIS growth rates over time.

However, internal cost modelling carried out for the Royal Commission regarded the estimate of 13,000 additional workforce as a reasonable benchmark in the context of the total disability support workforce and the needs of First Nations NDIS participants. The cost modelling assumed costs for more cultural safety training (for non-Indigenous support staff) and disability awareness training (for First Nations staff who need upskilling in supporting people with disability), plus scholarships to train First Nations people to become disability support workers. The total annual cost estimate is $37 million in 2024–25.[82]

We note the costings are subject to a very high degree of uncertainty, in part due to issues of data, assumption setting and the fluid policy environment. Further detailed research would be required to accurately cost the investment required in the First Nations disability workforce.

Furthermore, these costings are high-level, and investments are likely to require careful regional targeting to achieve the intended outcomes. A local, community-led approach is required to understand needs and the best ways to support the First Nations disability workforce. We believe the proposed First Nations Disability Forum is the appropriate mechanism through which resources should be distributed.

Parties to the DSSP should ensure appropriate funding is provided in the First Nations Disability Fund to build disability specific expertise into existing community-controlled organisations.

All Australian governments should contribute to the fund, which should be distributed via the First Nations Disability Forum as a resource to meet the DSSP and recorded in the Implementation Plans of government parties.

Need for a local workforce in remote areas

The Royal Commission heard there is a significant shortage of suitably skilled First Nations workers and locally based employees, especially in remote areas.[83] Building a local workforce is needed to increase availability of culturally safe disability services and reduce the need for participants to move off Country to access services.[84] A local workforce was also identified as being preferable to a fly-in-fly-out out model where providers are not based in the community. The evidence presented to us overwhelmingly supported ACCOs and ACCHOs having a central role in local workforce development.

During Public hearing 32, Synapse Australia Ltd (Synapse) gave evidence about its experience building a First Nations workforce.[85] It said an important aspect of ensuring the cultural safety of this workforce is independent, culturally informed mentoring of staff, separate to traditional line management.[86] Synapse outlined how this also provides an opportunity for the organisation to continually learn about how the workforce can be strengthened, and where it is being compromised.[87] It said culturally informed staff mentoring was essential to its local workforce model, but mentoring and workforce development has an organisational cost beyond NDIS pricing structures.[88]

In response to Counsel Assisting submissions to Public hearing 25, the Australian Government recognised that workforce availability, training and staff accommodation have affected service delivery for First Nations people in remote communities.[89] The Australian Government emphasised its commitment to 'the development of a comprehensive NDIS Workforce Strategy to ensure all NDIS participants can access the supports they need', administered by the Department of Social Services.[90]

The Australian Government suggested 'refining and broadening the scope of' a recommendation to support development of First Nations local workforces in remote communities. It suggested a remote workforce should be developed not merely for the NDIS, but 'with a view to them serving the broader care and support sector, including for example, the aged care and veterans' care sectors'.[91] We note that it is beyond our terms of reference to make a recommendation in those terms, but that it remains open to the Australian Government to expand the scope of Recommendation 9.13 below.

Recommendation 9.13 Remote workforce development

The First Nations Disability Forum and parties to the Disability Sector Strengthening Plan (DSSP) should collaborate to develop a strategy to develop First Nations local workforces in remote communities. The strategy should consider:

- funding for community-level assessments to determine:
  - existing infrastructure and resources
  - the capacity and willingness of the First Nations community-controlled sector to support local workforce development
  - the level of demand within the community
- that allocation of funding for local workforce development should include funding to build the capacity of family members to provide care
- the strategy should be co-developed and co-implemented with First Nations Community Controlled Organisations, noting their capacity, expertise and willingness to be involved. The involvement of First Nations Community Controlled Organisations must be adequately supported and funded.

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Appendix A

First Nations Engagement Principles

The Royal Commission's First Nations Engagement Principles recognise that First Nations people are the experts in their own experiences and have particular ways of working based on cultural protocols and governance systems.

We respect these systems and we took a flexible approach in how we engaged with First Nations people. We ensured that our engagements were culturally appropriate and took into account the relevant protocols, languages, capacity and leadership of existing First Nations governance structures. This included engaging with the relevant cultural leadership where appropriate, such as Elders and traditional custodians. We acknowledged and sought out the extensive specialist knowledge that exists in First Nations communities, especially in Aboriginal and Torres Strait Islander Community Controlled Organisations.

In undertaking our work with First Nations communities, we sought to create an environment in which a range of different voices could be heard, and in the way they preferred to be heard, whether spoken, signed, gestured or requiring Auslan or First Nations language interpreters.

Our engagements with First Nations communities had First Nations people at their centre. During our engagements, we committed to:

- apply a disability-led approach – ensuring the voices, perspectives and experiences of First Nations people with disability were central to our work
- use a rights-based framework – recognising and respecting the human and civil rights of First Nations people with disability
- ensure that engagements were culturally appropriate, safe and trauma-informed – recognising and respecting the culturally diverse needs and experiences of First Nations people with disability, and creating culturally, emotionally and physically safe environments for people to engage with the Royal Commission
- taking a strengths-based approach –recognising the inherent strengths of First Nations cultures and being guided by the priorities and aspirations of First Nations people
- respect self-determination – including the right of First Nations people with disability and the broader First Nations community to decide their level of participation in engagements with the Royal Commission
- ensure that engagements were participatory, accessible and responsive – taking steps to ensure our processes promoted culturally safe and inclusive participation.

More information about our engagements can be found in Volume 2, *About the Royal Commission.*

Royal Commission
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