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

Interim **Report**

October 2020

Interim Report

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Interim
Report

Wiradjuri artist and disability advocate Uncle Paul Constable Calcott has depicted the Disability Royal Commission story in a specially designed work of art titled ‘Respectful Listening’.

‘Respectful Listening’ depicts the story of seven Commissioners who, carrying their message stick, travel across many language groups and communities, depicted as multiple circles connected across many areas of the country. As they gather stories of violence, abuse, neglect, and exploitation from people with disability, these seven Elders will take these stories that have been entrusted to them and present them to a group of government representatives. These representatives will use the information from all these stories to suggest changes, to make sure people with disability and Elders are cared for, supported and respected in the future.

You can read the full story and what the colours and shapes in this artwork depict on our website.

30 October 2020

His Excellency General the Honourable David Hurley AC DSC (Retd)
Governor-General of the Commonwealth of Australia
Government House
CANBERRA ACT 2600

Your Excellency,

In accordance with the letters patent issued on 4 April 2019 and amended on 13 September 2019, we have made inquiries and now submit to you the *Interim Report of the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability*.

We are also submitting this report to their Excellencies the Governors of New South Wales, Queensland, South Australia, Tasmania, Victoria and Western Australia.

Yours sincerely,

The Honourable Ronald Sackville AO QC

Roslyn Atkinson

The Honourable Roslyn Gay Atkinson AO

Barbara Bennett

Ms Barbara Bennett PSM

Dr Rhonda Louise Galbally AC

Andrea J Mason

Ms Andrea Jane Mason OAM

Mr Alastair James McEwin AM

The Honourable John Francis Ryan AM

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 First Nations Elders past, present and emerging. We recognise their care for people and country, including First Nations men and women whose words and voices led to the establishing of this Royal Commission.

In particular, the Royal Commission acknowledges the Traditional Custodians of the lands on which our offices are based in Brisbane, Canberra and Sydney.

Content warnings

This report contains information that may be distressing to readers.

It includes accounts of violence against, and abuse, neglect and exploitation of, people with disability and references to suicide and self-harming behaviour.

In some first-hand accounts of violence, abuse, neglect and exploitation, people have told us of abusive or offensive language they have experienced or witnessed. As a result, some direct quotes in the report contain language that may be offensive to some people.

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

If you need support to deal with difficult feelings after reading this report, there are free services available to help you. These are listed below and in Chapter 6, 'Support for people engaging with the Royal Commission'.

Support services

People who engage with or are affected by the Royal Commission can get free support from a number of services. Some of these are listed here.

More information about organisations at the state and territory level that provide counselling support to people affected by the Royal Commission is available in Chapter 6 or on the Australian Government Department of Social Services website.[1]

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[1] 'Disability Royal Commission support services', Australian Government Department of Social Services, 25 June 2020. <https://www.dss.gov.au/disability-and-carers-disability-royal-commission-support-services/find-disability-royal-commission-support-services-in-your-area>

Blue Knot Foundation

Blue Knot offers a free and independent counselling and referral service for anyone affected by the Royal Commission, including people with disability, their families and support people. People can connect with Blue Knot by:

- telephone
- video conference
- webchat
- SMS.

Blue Knot operates a national telephone line (1800 421 468) between 9 am and 6 pm Australian Eastern Standard Time (AEST) from Monday to Friday and 9 am to 5 pm AEST on weekends and public holidays.

If you are deaf or have a hearing or speech impairment, telephone the National Relay Service on 133 677 and give 02 6146 1468 as the number you want to call.

If you need support in another language you can:

- call Blue Knot's national telephone line (1800 421 468) and ask for an interpreter, or
- use the free Translating and Interpreting Service (TIS) by calling 131 450 and ask to be connected to Blue Knot's national telephone line (1800 421 468).

For information: www.blueknot.org.au/

Beyond Blue Support Service

Telephone 1300 224 636 (24 hours/7 days), chat online (3 pm to 12 am AEST/7 days) or email for free, short-term counselling, advice and referral services.
For information: www.beyondblue.org.au/get-support/get-immediate-support

Lifeline Crisis Support

Speak to a crisis support worker by telephone on 13 11 14 (24 hours/7 days) or chat online (7 pm – midnight/7 nights). This confidential service provides support when you are feeling overwhelmed, having difficulty coping or thinking about suicide.
For information: www.lifeline.org.au/get-help/get-help-home

1800RESPECT

Telephone 1800 737 732 or chat online (both 24 hours/7 days) for support if you are affected by sexual assault or domestic and family violence or abuse.
For information: www.1800respect.org.au/

Foreword by the Chair

The interim report of the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (the Royal Commission) complies with the direction in our terms of reference to submit to the Governor-General an interim report not later than 30 October 2020.

The interim report has been written in circumstances that were not, and could not have been, anticipated when the Royal Commission was established in April 2019. The COVID-19 pandemic has affected, in one way or another, every person in this country. With the exception of people in aged care facilities, no group has been more profoundly affected than people with disability.

The Royal Commission itself has not been immune from the lockdowns and other consequences of the pandemic. We have experienced substantial interruptions to our scheduled program of public hearings and to our engagement with people with disability, their families, advocates and supporters. Even so, as the interim report shows, we have made considerable progress in discharging our heavy responsibilities.

I particularly wish to pay tribute on behalf of the Royal Commission to all people with disability and their families and supporters who have shared their experiences with us and offered their insights into the issues we are required to investigate. The experiences and insights of people with disability and their families and supporters are the foundations on which the work of the Royal Commission is built. The interim report is an important milestone towards the completion of that work.

Our task

The Chair's opening statement at the Royal Commission's ceremonial public hearing, held in Brisbane on 16 September 2019, identified four particularly significant aspects of the terms of reference. These four matters have been, and remain, central to the scope of our inquiries and how we undertake those inquiries.

First, the voices of people with disability are at the forefront of our work. People with disability are the ones who have experienced violence, abuse, neglect and exploitation and who can recount those experiences. They understand only too well the barriers to a more inclusive society. As we have heard in public hearings, submissions, community forums and in other ways, people with disability have strong views – often informed by their personal experiences – as to the measures needed to achieve the goals stated in the terms of reference.

People with disability and their families and supporters have contributed greatly to our inquiries through submissions and responses to our issues papers, community forums, private sessions and other forms of engagement. We have heard the voices of people with disability at public hearings and benefited from powerful and often moving first-hand evidence of the violence, abuse, neglect and exploitation they have experienced.

The 36 individual narratives included in the interim report provide a small sample of what we have heard in the course of our work so far.[1] These accounts bring home that people with disability can experience violence, abuse, neglect or exploitation in almost every aspect of their lives. The experiences also bring home the profound consequences that can flow from these experiences, for both people with disability themselves and their families.

The accounts in the interim report include children being subjected to cruel bullying and humiliating restraints in education settings; serious neglect and misdiagnoses of people with cognitive disability within the health care system, sometimes as the result of 'diagnostic overshadowing' (where symptoms of disease or injury are wrongly attributed to a person's disability); physical and sexual abuse of people living in supported accommodation perpetrated by staff who are meant to provide care for residents; and discrimination and abuse of people with disability at their place of employment.

The voices of people with disability are reflected in the policy themes and issues that the Royal Commission has identified for further inquiry and also influence the subject matter of hearings. For example, the first hearing held in August 2020 after our public activities resumed inquired into the impact of the COVID-19 pandemic on people with disability and the adequacy of the actions of governments to protect them. The decision to choose COVID-19 as the theme for that hearing was based on the numerous accounts given by people with disability to the Royal Commission on social media and elsewhere of the trauma and neglect they experienced during the pandemic. People with disability will remain at the centre of our work during the life of the Royal Commission.

Second, the Royal Commission's functions and responsibilities are extremely broad. Among other things, we are required to inquire into violence against, and abuse, neglect and exploitation of, people with disability **in all settings and contexts**. The interim report demonstrates that people with disability experience violence, abuse, neglect and exploitation in a range of settings and contexts and at various stages of their lives.

The interim report records the difficulties of reaching all people with disability who have experienced violence, abuse, neglect or exploitation. For example, people with disability living in closed or segregated environments and First Nations people with disability living in remote communities are not likely to respond to conventional techniques for eliciting submissions or accounts of personal experiences.

We must therefore make strenuous and innovative efforts to engage with as many people with disability as possible and to ensure they receive appropriate support to do so safely and comfortably. The measures that have been put in place have been devised and implemented by the Royal Commission's Community Engagement team under the guidance particularly of Commissioners Galbally and McEwin. The interim report records measures taken so far to engage with people with disability. These efforts have been maintained during the pandemic and will continue throughout the life of the Royal Commission.

Third, the terms of reference direct us to have regard to the multi-layered experiences of people with disability, particularly those from First Nations and culturally and linguistically diverse communities. The interim report explains the steps we have taken to expose the nature and extent of violence, abuse, neglect and exploitation experienced by these particular groups and to encourage their engagement with the Royal Commission.

It is unfortunate that the extraordinary and fruitful efforts made under the leadership of Commissioner Mason to reach out to First Nations people with disability have been hampered by COVID-19 travel restrictions and delays in holding planned public hearings on First Nations issues in the Northern Territory. It is also unfortunate that the Royal Commission's program of engagements with people and representative organisations from culturally and linguistically diverse communities has to some extent been affected by the pandemic. Nonetheless, in each case important connections have been firmly established and we have continued our engagements online.

In due course we shall have to consider the effect of the pandemic on the timing for the completion of the Royal Commission's work. One way or another we will make up for any lost ground in our engagements with First Nations and culturally and linguistically diverse people with disability.

Fourth, we have adopted an approach that is informed by human rights, especially the rights recognised by the United Nations *Convention on the Rights of Persons with Disabilities* (*CRPD*) to which Australia is a party.[2] As stated in Chapter 16, 'Our theoretical approaches', we seek to translate the human rights recognised in the *CRPD* into practicable and sustainable policies and practices that will promote the right of people with disability to live free from violence, abuse, neglect and exploitation.

Chapter 16 also draws on the work of disability theorists to explain the theoretical models that guide our work. This chapter recognises that a sound theoretical framework is the necessary foundation for an effective reform agenda.

Our aim

The interim report records what we have done in the first 15 months of the Royal Commission's existence and outlines what we intend to do over the remainder of the Royal Commission's life. By its nature, the interim report does not attempt to comprehensively analyse all the issues raised by the terms of reference.

Even so, our ultimate aim is nothing if not ambitious. We seek to transform community attitudes and bring about changes to policies and practices that have exposed people with disability to violence, abuse, neglect and exploitation and that denied them 'full and effective participation and inclusion in society'.[3] Only then will Australia fully achieve the goal of a more inclusive society that supports the independence of people with disability and their right to live free from violence, abuse, neglect and exploitation.

A tribute

The research for and the writing of the interim report have taken place in uniquely difficult circumstances. On behalf of all Commissioners I wish to pay tribute to the dedication, skill and thoroughness demonstrated by the many staff of the Royal Commission who have contributed to the drafting of the interim report. Their enthusiasm and commitment to the work and objectives of the Royal Commission have overcome obstacles that had the potential to be insurmountable.

The Commissioners are deeply indebted to all who have been involved in or supported the preparation of the interim report.

The Hon Ronald Sackville AO QC

Chair

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

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1 As explained in the interim report, the narratives have been de-identified and do not represent findings by the Royal Commission. They are summaries of experiences people have shared with us in submissions and private sessions.

2 *Convention on the Rights of Persons with Disabilities*, opened for signature 30 March 2007, 999 UNTS 3 (entered into force 3 May 2008).

3 *Convention on the Rights of Persons with Disabilities*, opened for signature 30 March 2007, 999 UNTS 3 (entered into force 3 May 2008), art 3(c).

Contents

About this report

The letters patent for the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (the Royal Commission) require the Royal Commission to submit an interim report to the Governor-General by 30 October 2020 and a final report by 29 April 2022.

This report is based on the Royal Commission's work from 5 April 2019 to 31 July 2020. It draws on what we have heard so far from people with disability and their families and supporters, as well as many organisations, our First Nations Peoples Strategic Advisory Group and other experts who have provided their insights.

On 16 March 2020, the Royal Commission suspended all activities involving gatherings of people or close contact between individuals due to the COVID-19 pandemic and concerns for the health and safety of people with disability, the broader community and members of staff.

Despite this, the Royal Commission's work continued during the pandemic. We received submissions, published issues papers, progressed our research and policy work and prepared for future public hearings. We also continued to engage with people with disability, their supporters and stakeholders online and by telephone and mail. The Royal Commission resumed public activities in August 2020 and carefully adheres to all official advice regarding physical distancing and other public health measures.

In addition to this interim report, the Royal Commission has committed to publishing progress reports at intervals of approximately six months. The reports provide a brief account of the Royal Commission's activities over the preceding half-year period. The *First Progress Report* of the Royal Commission was published in December 2019 and covered the Royal Commission's program from its formal establishment in April 2019 until 30 November 2019.[1] The *Second Progress Report* summarised the work carried out by the Royal Commission during the period 1 January 2020 and 30 June 2020.[2]

Our gratitude to those who have shared their personal experiences

The Royal Commission is grateful to the many people who have shared their personal experiences of violence, abuse, neglect and exploitation with our inquiry to date. We recognise the strength shown by people with disability, their families and supporters who have shared experiences that have often caused significant pain or trauma. Hearing these experiences is critical for us to understand the nature and extent of violence against, and abuse, neglect and exploitation of, people with disability in Australia, and how it can be prevented.

We encourage anyone who has information relevant to our inquiry to engage with the Royal Commission. For information on ways to do this, see Chapter 19, 'Our future direction'.

Conveying personal experiences

The voices of people with disability and others who have shared their experiences with us are included throughout this report. With the consent of those providing the information, we have used quotes from submissions we have received, and from accounts given by participants at community forums, meetings and workshops. We have also used evidence from witnesses who gave evidence at our public hearings. Some witnesses at our public hearings were given pseudonyms, which we use when quoting their evidence. When we have included quotes, we have not amended the words or spelling used.

As stated earlier in this report, in some first-hand accounts of violence, abuse, neglect and exploitation, people have told us of abusive or offensive language they have experienced or witnessed. As a result, some quotes in this report contain language that may be offensive to some people.

We also use de-identified narratives throughout this report to reflect some of the accounts people have shared with us. 'Narratives' are summaries of the experiences people have shared with our inquiry through submissions or private sessions and given consent for us to use. We have tried to faithfully represent people's accounts of their experiences. Due to the length of some submissions, some narratives may only be a 'snapshot' of the full submission.

'De-identified' means that real names have been replaced with pseudonyms and some details have been left out to protect people's identities. De-identification of narratives enables the Royal Commission to protect both those who have shared their accounts but may not want their identity disclosed, and people and organisations referred to in these accounts who have not had an opportunity to respond to any allegations made against them. In this way, de-identified narratives enable the Royal Commission to inform the public of the often terrible personal experiences of violence against, and abuse, neglect and exploitation of, people with disability, without breaching its legal obligations to afford procedural fairness to all.

In contrast to statements tendered at or oral evidence given at public hearings, the information a person provides in a submission or during a private session is not evidence and the person providing the account is not a witness. The narratives included in this report are not representative of any factual findings of the Royal Commission and any views expressed are those of the person who shared the information with us, not the Commissioners.

Language used in this report

The way language is used can be powerful. The Royal Commission aims to use current and respectful terminology. The use of inappropriate words and language to describe people with disability and the violence, abuse, neglect and exploitation experienced by people with disability can harm them and silence their voices. Conversely, respectful language choices can promote awareness, inclusion and empowerment.

People with disability are the experts when it comes to language in this area. In deciding on the language we use, we have been guided by the definitions and principles in the United Nations *Convention on the Rights of Persons with Disabilities*[3] and have consulted with disability experts. We recognise that people with disability have varying preferences about language and that language is constantly evolving. We will continue to listen to what people with disability tell us about language as the Royal Commission progresses. How we define terms may change between this interim report and our final report.

In this report, we use the phrases 'we have heard' and 'we have been told' when discussing information we have received through public hearings, submissions, community forums and meetings, private sessions and responses to issues papers. This language does not indicate that the Royal Commission has made findings of fact about this information.

Person-first language

The Royal Commission generally uses person-first language in this report. This means we refer to individuals as people first, rather than putting a disability, impairment, condition or diagnosis first. For example, we refer to 'people with disability', not 'the disabled' or 'disabled people'. This approach seeks to avoid labelling people by identifying them primarily by their disability.

However, we recognise that some people with disability and their representative groups may have different preferences about how they describe themselves and their disability. Some individuals and groups prefer identity-first language, which reflects the belief that disability is a core part of a person's identity. For example, a person may prefer to be referred to as a 'Deaf person' rather than a 'person who is Deaf' or an 'autistic person' rather than a 'person with autism'. Some individuals and groups may also prefer to use 'disabled person' rather than 'person with disability', reflecting their understanding of disability as arising from social barriers. When people have told us how they prefer to describe themselves, we have used the description they prefer.

Key terms and definitions

Key terms used in this report are defined in the Glossary. A list of acronyms and other abbreviations used appears before the Glossary.

The Royal Commission has adopted the following definitions for key terms used in this report. As noted above, how we define terms may change between this report and our final report.

Disability

Disability is an evolving concept that results from the interaction between a person with impairment(s) and attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis with others.[4]

For more on this, see Chapter 16, 'Our theoretical approaches', which includes discussion of theories of disability and how concepts and models of disability have changed over time.

People with disability

Based on the terms of reference in the Royal Commission's letters patent, the term 'people with disability' is defined as people with any kind of impairment, whether existing at birth or acquired through illness, accident or the ageing process, including cognitive impairment and physical, sensory, intellectual and psychosocial disability.[5]

Some people prefer to identify as 'disabled people'.

Violence, abuse, neglect and exploitation

For the purposes of this Royal Commission, violence and abuse are best understood together. Violence and abuse include assault, sexual assault, constraints, restrictive practices (physical, mechanical and chemical), forced treatments, forced interventions, humiliation and harassment, financial and economic abuse and significant violations of privacy and dignity on a systemic or individual basis.

Neglect includes physical and emotional neglect, passive neglect and wilful deprivation. Neglect can be a single significant incident or a systemic issue that involves depriving a person with disability of the basic necessities of life such as food, drink, shelter, access, mobility, clothing, education, medical care and treatment.

Exploitation is the improper use of another person or the improper use of or withholding of another person's assets, labour, employment or resources, including taking physical, sexual, financial or economic advantage.

Other versions of this report

This interim report is available on the Royal Commission website in the following formats:

- Easy Read summary
- Auslan video summary.

Braille versions of the report are available on request. To request a braille version, please contact the Royal Commission:

- email – DRCenquiries@royalcommission.gov.au
- telephone – 1800 517 199 or +61 7 3734 1900, 9 am to 5 pm AEST from Monday to Friday, excluding national public holidays
- post – GPO Box 1422, Brisbane Qld 4001.

Royal Commission data in this report

The quantitative information in this report about the Royal Commission's early work is current at 31 July 2020, unless otherwise stated.

Endnotes

1 Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, *First Progress Report*, December 2019. <https://disability.royalcommission.gov.au/publications/first-progress-report>

2 Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, *Second Progress Report*, August 2020. <https://disability.royalcommission.gov.au/publications/second-progress-report>

3 *Convention on the Rights of Persons with Disabilities*, opened for signature 30 March 2007, 999 UNTS 3 (entered into force 3 May 2008).

4 *Convention on the Rights of Persons with Disabilities*, opened for signature 30 March 2007, 999 UNTS 3 (entered into force 3 May 2008), preamble para 5.

5 *Letters Patent* (Cth), 4 April 2019 amended 13 September 2019, recitals.

Summary

Purpose of this report

> What is happening to people is not okay
> and the stories need to be told.[1]

The establishment of the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (Royal Commission) was largely the result of determined and persistent advocacy over many years by people with disability and their supporters. They urged successive governments to take responsibility for and investigate widespread violence against, and abuse, neglect and exploitation of, people with disability.

The letters patent establishing the Royal Commission direct us to submit an interim report to the Governor-General by 30 October 2020.[2] This report has been prepared in accordance with that direction. The letters patent direct that the Royal Commission's final report should be presented by 29 April 2022.[3]

This Summary provides a brief overview of the 19 chapters of the interim report. It also recounts the principal issues addressed in the interim report.

They are:

- the reasons why the Royal Commission is needed
- the theoretical models influencing the work of the Royal Commission
- the activities undertaken by the Royal Commission to date, including public hearings, private sessions, engagement with the disability community, publication of issues papers, and careful consideration of submissions, responses to issues papers and what we have been told through community engagement activities
- the areas the Royal Commission has identified as warranting further inquiry, including those highlighted by evidence given at the first three public hearings
- the cumulative disadvantages experienced by particular groups of people with disability, especially First Nations people and members of culturally and linguistically diverse communities.

The interim report incorporates the voices of people with disability and their supporters who have shared their experiences with the Royal Commission. It includes narratives drawn from accounts in submissions and at private sessions. The narratives have been anonymised to protect the privacy of the people who have told us their experiences. We have also drawn on the contributions of experts, researchers and representatives of governments and other agencies.

Our seven Commissioners have diverse backgrounds and expertise. We acknowledge the expertise of the Commissioners with disability: Commissioner Rhonda Galbally AC and Commissioner Alastair McEwin AM, who are both long-term disability advocates. We also acknowledge the expertise of the Royal Commission's Disability Strategic Engagement Group and all Royal Commission staff with disability.

We acknowledge the courage required for people with disability, their families and supporters to share their experiences with us at a private session, public hearing or community forum.

The Royal Commission acknowledges the ongoing custodianship of Australia's First Nations peoples of our lands, seas and waters. We pay our respects to all First Nations people with disability and recognise the distinct contributions they make to Australian life and this inquiry. We are guided by the leadership of Ngaanyatjarra and Karonie woman, Commissioner Andrea Mason OAM, the expertise of the First Nations Peoples Strategic Advisory Group, and all First Nations staff at the Royal Commission.

Establishment of the Royal Commission

The Prime Minister, the Hon Scott Morrison MP, announced the establishment of the Royal Commission on 18 February 2019. The letters patent containing the Royal Commission's terms of reference were issued on 4 April 2019 after extensive consultation with people with disability and the disability sector.[4]

The letters patent appoint the Hon Ronald Sackville AO QC as the Chair of the Royal Commission. He is supported by six Commissioners:

- the Hon Roslyn Atkinson AO
- Ms Barbara Bennett PSM
- Dr Rhonda Galbally AC
- Ms Andrea Mason OAM
- Mr Alastair McEwin AM
- the Hon John Ryan AM.

The terms of reference direct the Royal Commission to inquire into what governments, institutions and the community should do to report, investigate, respond to, prevent and better protect people with disability from experiencing violence, abuse, neglect and exploitation.[5] They also direct the Royal Commission to inquire into what should be done to promote a more inclusive society that supports the independence of people with disability and their right to live free from violence, abuse, neglect and exploitation.[6] In addition, the terms of reference direct us to have regard to the multi-layered experiences of people with disability, and the particular situation of First Nations people with disability and culturally and linguistically diverse people with disability.[7]

The terms of reference of this Royal Commission are distinctive in two major respects. The first is that they are extraordinarily broad. We are required to examine all forms of violence against, and abuse, neglect and exploitation of, people with disability in 'all settings and contexts'.[8] The second is the express recognition that people with disability should be central to the processes that inform best practice decision-making on what Australian governments and others should do to prevent and respond to violence against, and abuse, neglect and exploitation of, people with disability.[9] This underpins our commitment to ensuring that people with disability are central to our work.

We are conscious that people with disability who have been exposed to violence, abuse, neglect and exploitation have often experienced trauma. Our approach aims to minimise, to the greatest extent possible, the risk of re-traumatising people engaging with this inquiry.

Overview of this report

This interim report consists of 19 chapters in four parts.

Part A: About the Royal Commission

Chapter 1, 'Why this Royal Commission is needed' provides an overview of the history of discrimination, disadvantage and maltreatment experienced by people with disability. It traces key policy and social changes achieved through the advocacy of the disability rights movement. The chapter outlines the events that led to this Royal Commission and the consultations that informed our terms of reference. The chapter concludes with one person's experience to illustrate the importance of our task.

Chapter 2, 'Our Chair and Commissioners' outlines the backgrounds of our Chair and Commissioners.

Chapter 3, 'Our terms of reference' describes the scope of the Royal Commission.

Chapter 4, 'Nature and powers of the Royal Commission' explains key provisions of the *Royal Commissions Act 1902* (Cth), the powers of the Royal Commission and how the Act regulates the conduct of our inquiry.

Chapter 5, 'Our organisation' provides an overview of our organisation and the values that inform the work of the Royal Commission. It describes our Accessibility and Inclusion Strategy, which underpins our work by guiding how we communicate with the community, recruit and train staff, and establish premises, hearing rooms and other venues where we engage with the disability community and the general public.

Part B: How we do our work

Chapter 6, 'Support for people engaging with the Royal Commission' describes the trauma-informed approach we take to all aspects of our inquiry and outlines the support provided to people who contribute.

Chapter 7, 'Public hearings' describes the formal proceedings through which witnesses give evidence, under oath or affirmation, about events and issues relevant to the Royal Commission's terms of reference. It describes how public hearings enable people with disability, their families and supporters to share experiences of violence, abuse, neglect and exploitation. Experts, advocacy groups, service providers, academics and government agencies may also give evidence.

Chapter 8, 'Submissions' outlines how individuals and organisations are able to share with the Royal Commission their experiences, insights and proposals for change. As the chapter explains, submissions can be about any issues that fall within our terms of reference and can be made in a variety of ways, including in writing, over the telephone, as videos or as artwork.

Chapter 9, 'Community engagement' sets out our approach to how we engage with people with disability and the wider community. It also records our approach to targeted engagement with First Nations communities, culturally and linguistically diverse people with disability, people with cognitive disability and people with disability who live or work in closed or segregated environments.

Chapter 10, 'Private sessions' describes how individuals can confidentially share their experiences with a Commissioner in a safe, supportive and accessible environment. The chapter outlines how private sessions help the Royal Commission to better understand the impact of violence against, and abuse, neglect and exploitation of, people with disability, and to explore ideas as to how these experiences can be prevented.

Chapter 11, 'Research and policy' provides an overview of our research agenda, which explores (among other topics) the history, nature and extent of violence, abuse, neglect and exploitation experienced by people with disability. Chapter 11 also outlines our policy work, which is directed to the systemic factors that contribute to violence against, and abuse, neglect and exploitation of, people with disability and to the development of recommendations that will lead to lasting change.

Part C: Our work to date

The Royal Commission's ceremonial opening sitting was held in Brisbane on 16 September 2019 and is referred to as 'Public hearing 1'.

Chapters 12 to 14 provide an overview of the first three public hearings held by the Royal Commission.

- Chapter 12 outlines Public hearing 2: Inclusive education in Queensland – preliminary inquiry
- Chapter 13 outlines Public hearing 3: The experience of living in a group home for people with disability
- Chapter 14 outlines Public hearing 4: Health care and services for people with cognitive disability.

These chapters summarise the key themes that emerged from the evidence presented at the hearings and outline the areas for future inquiry that have arisen from each hearing. A detailed report of each public hearing is available on the Royal Commission website.

Chapter 15, 'Nature and extent of violence against, and abuse, neglect and exploitation of, people with disability' describes the importance of high-quality data. There is good data on the number of people with disability in Australia but little on the violence, abuse, neglect and exploitation experienced by people with disability, particularly for certain groups such as First Nations people with disability, people with disability from culturally and linguistically diverse communities, and people with disability living in closed or segregated environments. The chapter outlines the Royal Commission's strategy to address these gaps.

Part D: Emerging themes and our future direction

Chapter 16, ‘Our theoretical approaches’ outlines four approaches that come from our terms of reference and guide our work: human rights, disability theory, intersectionality[10] and life course.

Chapter 17, ‘Emerging themes and key issues’ discusses the themes and key issues that have emerged in the first phase of our inquiry. Some themes and issues have been the subject of detailed evidence at the public hearings. Others have been identified in submissions, responses to issues papers and from what we have heard through our community engagement activities.

Chapter 18, ‘First Nations people with disability’ outlines what we have heard about what it means to live as a First Nations person with disability in Australia. Chapter 18 identifies key issues that we had planned to examine in hearings during the first half of 2020 but which have had to be postponed due to the COVID-19 pandemic. The issues will now be considered as soon as we are able to resume these hearings safely.

Chapter 19, ‘Our future direction’ describes how the Royal Commission will build on our work to date. It details how we will draw on what we learn through public hearings, submissions, community engagement, private sessions, research and policy work to deepen our understanding of the emerging themes and key issues and develop recommendations to prevent violence against, and abuse, neglect and exploitation of, people with disability for publication in our final report.

Four appendices provide information concerning:

- A: Letters patent
- B: Past reports and inquiries
- C: Key activities and publications to date
- D: A brief overview of the National Disability Insurance Scheme (NDIS).

They are followed by a list of the acronyms and abbreviations used in this report, and the Glossary.

Why this Royal Commission is needed

The activism and advocacy of the disability rights movement since the 1970s and 1980s has led to substantial changes in Australian legislation, policy and practice. The achievements include the enactment of the *Disability Discrimination Act 1992* (Cth) and Australia’s ratification of the United Nations *Convention on the Rights of Persons with Disabilities* (*CRPD*) on 17 July 2008.

Despite this progress, the high-profile cases of sexual abuse of people living in Yooralla group homes in Victoria between 2011 and 2014[11] brought to the public’s attention what people with disability and their advocates have long known: violence against, and abuse, neglect and exploitation of, people with disability persist in Australia.

The number of people with disability in Australia

The Australian Bureau of Statistics defines disability as ‘any limitation, restriction or impairment which restricts everyday activities and has lasted, or is likely to last, for at least six months’.[12] A series of questions about whether a person needs assistance or has difficulty with, or uses aids or equipment to perform, different types of activities are used to determine disability. The Australian Bureau of Statistics *Survey of Disability, Ageing and Carers*, which is the best available source of information on the number of people with disability in the Australian population, states that there were around 4.4 million people with disability in Australia in 2018.[13]

The older a person is, the more likely it is they will have a disability. Table 1 shows that in 2018, 8.2 per cent of children aged under 18 had disability, while around 13 per cent of adults aged 18–64 had disability and nearly 50 per cent of adults aged 65 and over had disability.[14] More than two in five people with disability were aged over 65 years.

Table 1: Number and percentage of people with disability by age group, 2018

Age group	Number of people with disability (‘000’)	Percentage of age group that has disability	Percentage of population with disability
Children aged under 18	453.7	8.2%	10.4%
Adults aged 18–64	1969.7	12.9%	45.1%
Older adults aged 65+	1941.5	49.6%	44.5%
Total	**4367.2**	**17.7%**	**100.0%**

Note: The numbers of people with disability in each age group do not add up to 4367.2 because the Australian Bureau of Statistics changes some numbers to protect the confidentiality of people completing the survey.

Source: Australian Bureau of Statistics (2019).

The percentage of the Australian population with disability has decreased over time, although the actual number of people with disability has increased as the population has grown.[15]

The Australian Bureau of Statistics *National Aboriginal and Torres Strait Islander Health Survey* suggests that around 306,100 First Nations people had a disability in 2018–19, representing 38 per cent of the First Nations population (see Table 2).[16] The proportion of First Nations people with disability is considerably higher than the proportion of people with disability in the general population. More than one in five First Nations children (aged under 18) are children with disability, and children accounted for almost one-quarter of all First Nations people with disability.[17]

The Australian Bureau of Statistics does not provide data to break down First Nations adults with disability into separate age categories. In Table 2, we have separated statistics for First Nations people with disability into two groups (children and adults) rather than three groups (children, adults and older adults) as we did for the general population.

Table 2: Number and percentage of First Nations people with disability by age group, 2018–19

Age group	Number of First Nations people with disability ('000')	Percentage of First Nations population	Percentage of First Nations population with disability
Children (aged under 18)	73.0	22.3%	23.9%
Adults (aged 18+)	233.6	48.1%	76.4%
Total	**306.1**	**37.6%**	**100.0%**

Note: The numbers for each age group of First Nations people with disability do not add up to 306.1 in the 'Total' row because the Australian Bureau of Statistics changes some numbers to protect the confidentiality of people completing the survey.

Source: Australian Bureau of Statistics (2019).

'Cultural and linguistic diversity' is an expression that is difficult to define. Researchers tend to use the expression to describe communities for whom English is not the main language or whose cultural norms differ from the wider community. The breadth of this description makes it difficult to measure how many people with disability also identify as culturally and linguistically diverse. Data suggests there are around 136,000 people with disability who were born in a country where English was not the main language *and* who speak a language other than English at home and who do not speak English well or at all.[18] This is around 0.6 per cent of the Australian population and around 3 per cent of people with disability. However, the number of people with disability who identify as culturally and linguistically diverse is likely to be considerably higher.

Data on violence, abuse, neglect and exploitation

In Australia, almost two-thirds of people with disability have experienced violence in their lifetime, and people with disability are twice as likely as people without disability to experience violence in a 12-month period.[19] Of women with disability aged 18–64, 32 per cent experience sexual violence in a 12-month period, which is twice the rate of women without disability in the same age bracket. This pattern is repeated across different groups of people with disability.

The 2018–19 Australian Bureau of Statistics *National Aboriginal and Torres Strait Island Health Survey* suggests that First Nations adults with disability experience high rates of violence.[20]

While Australia has improved its collection and reporting of data on violence and abuse experienced by people with disability, critical data gaps remain. In 2016, the Australian Bureau of Statistics *Personal Safety Survey* included questions to identify people with disability and the type of impairment they have. However, this survey excludes children, people in custody, people who live in institutional settings such as aged care homes, and people who do not speak English or who cannot respond confidentially to questions. This means people with disability are more likely to be excluded from the survey than people without disability. People with communication disability, culturally and linguistically diverse people with disability and people with intellectual disability are particularly likely to be excluded.

There is no nationally consistent data on neglect or exploitation experienced by people with disability.

There is also no reliable publicly available data on the violence, abuse, neglect or exploitation experienced by:

- culturally and linguistically diverse people with disability, including people granted protection visas as refugees and humanitarian migrants
- lesbian, gay, bisexual, trans and gender diverse, intersex, queer or questioning people with disability
- children and young people with disability
- First Nations children with disability
- people with disability experiencing homelessness.

We commissioned researchers at the Centre of Research Excellence in Disability and Health to review the available data on the extent of violence, abuse, neglect and exploitation experienced by people with disability. The researchers concluded that:

> the historical omission of people with disability from national data collections, and the lack of up-to-date analyses where data on violence and disability are available, means there is limited empirical evidence to inform governments, institutions and the community about best practices in prevention and response.[21]

This absence of data means that nobody can estimate with confidence the levels of violence, abuse, neglect and exploitation experienced by people with disability. This makes it difficult for governments and other agencies with policy-making responsibilities to design and implement effective policies and programs. Data is needed to:

- set goals
- measure progress
- enable others to hold governments and organisations accountable for delivering those goals
- track progress on action plans such as the National Disability Strategy
- determine whether the Australian Government is meeting its obligations under the *CRPD*.

Without detailed data, it is not possible to assess whether a particular policy or program achieves its intended outcome, whether for people with disability as a whole or for particular groups within the disability community. The lack of useful data has emerged as a major theme in our work so far.

The Royal Commission will examine these data gaps through our ongoing work. Our areas of further inquiry are outlined at the end of this Summary.

Our theoretical approaches

> It's okay to talk about violence, abuse and neglect ... but a lot of people don't even realise they are victims. Education is key. We all need a standard of rights that we all must abide by. PWD [people with disability] have no idea what their rights even are the majority of the time.[22]

The Royal Commission is informed by four main theoretical approaches. These approaches, which come from our terms of reference, are human rights, disability theory, intersectionality – which describes the unique discrimination that arises from the interaction of ableism with other forms of oppression such as racism, sexism, ageism or homophobia – and life course.[23] The Royal Commission draws on existing knowledge in these areas to help us understand the forces that shape the lives of people with disability and make recommendations for lasting change.

We are guided by the human rights frameworks developed in a series of United Nations conventions, most notably, the *CRPD*.[24] The *CRPD* sets out obligations for the Australian Government to undertake to ensure and promote the full realisation of all human rights and fundamental freedoms for all persons with disability, without discrimination of any kind on the basis of disability.

Human rights play an important role beyond just imposing legal obligations on government. They reflect a set of values, such as the dignity, autonomy, freedom and equality of all people. The *CRPD* articulates values and standards by which people with disability should be treated and informs community values and standards. The human rights framework assists in understanding why people with disability experience violence, abuse, neglect and exploitation and will inform the recommendations we make.

In its preamble, the *CRPD* says that:

> disability is an evolving concept and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others.[25]

This definition is informed by theories and models of disability developed by advocates and scholars. In particular, the social model of disability challenges prevailing assumptions that disability is an individual medical problem or a tragedy to be eliminated, cured or hidden away. The social model shifts the focus from a person's impairment to the social structures, barriers and attitudes that exclude and disempower people. Some disability theorists have argued that the social model may not always be of great assistance in formulating proposals for change. But its profound influence in reshaping attitudes and the understanding of disability is undeniable.

People with disability face barriers to their full and equal participation in society. However, individual people's experiences vary and are influenced not only by the nature of their disability but also other factors like their age, sex, gender, gender identity, sexual orientation, intersex status, ethnic origin, socio-economic status and race. Our terms of reference require us to give attention to these multi-layered experiences.[26] To do this, we use an intersectional approach to help us understand how prejudice and oppression based on ableism interacts with other forms of oppression – such as racism, sexism, ageism or homophobia – to create unique forms of disadvantage and discrimination.

Finally, the life course approach is taken from the social sciences. It helps us to understand individual pathways and trajectories in the context of larger social changes and trends.

What we have done so far

The Royal Commission gathers information on and evidence about individual experiences and systemic issues to understand the nature and extent of violence against, and abuse, neglect and exploitation of, people with disability and inform our recommendations. Our work so far has included public hearings, submissions, community engagement, private sessions, research and policy work.

Impact of the COVID-19 pandemic

On 16 March 2020, the Royal Commission suspended all activities involving gatherings of people or close contact between individuals due to the COVID-19 pandemic. This was unavoidable in view of the risks to health, especially for people with disability but also to staff and members of the Royal Commission. Notwithstanding the suspension of public activities, the work of the Royal Commission has continued during the COVID-19 pandemic. That work has included preparing the interim report and reports on the first three public hearings, publishing issues papers, processing submissions and responses to issues papers, finalising the research agenda and continuing to engage with people with disability, their supporters and advocates through technology.

The Royal Commission resumed public activities in August 2020 and carefully adheres to all official advice regarding physical distancing and other public health measures. We will continue to use technology to enable people to participate in the Royal Commission's activities and engagements while COVID-19 restrictions remain in place.

Our work so far

As at 31 July 2020, the Royal Commission has held our ceremonial opening sitting and three public hearings.[27] A public hearing on the 'Experiences of people with disability during the ongoing COVID-19 Pandemic as at August 2020' is planned for 18–21 August 2020, with a number more planned for the remainder of 2020. The Royal Commission has held eight community forums, where Commissioners and more than 560 registered participants listened to 87 people share their experiences of violence, abuse, neglect and exploitation.

We have received 1237 submissions, including from people with disability, their family members, advocates and organisations. We have held nine workshops, published nine issues papers and received 295 responses to those papers. We have a number of research projects underway as part of our research agenda and will publish reports on our website as the projects are completed.

The Royal Commission opened registrations for private sessions in January 2020 and the first five were held in February 2020. From March 2020 to July 2020, we suspended face-to-face private sessions due to the COVID-19 pandemic. However, 12 private sessions were conducted by telephone and videoconference during this time.

The Royal Commission's community engagement strategy sets out the aims of our community engagement, as well as who we engage with and how we do so. We have established the Disability Strategic Engagement Group to strengthen our engagement with the disability sector.

Emerging themes and key issues

We have heard about the violence, abuse, neglect and exploitation experienced by people with disability in many different systems including education, homes and living arrangements, health, the justice system and the NDIS.

Like everyone, people with disability live complex and multi-faceted lives that go beyond their interaction with systems and services. We have also heard about the experiences of people with disability in the context of their relationships and participation in the community and the economy, including at work. People with disability have also told us how they have been affected by the COVID-19 pandemic and government responses to it.

Emerging themes

A number of themes have emerged as particularly pertinent to the independence of people with disability and their right to live free from violence, abuse, neglect and exploitation. The themes include:

- choice and control
- attitudes towards disability
- segregation and exclusion
- restrictive practices
- access to services and supports
- advocacy and representation
- oversight and complaints
- funding.

Choice and control

People with disability have the right to control their own lives, to make their own decisions and to exercise choice. This can be described as the right to autonomy or independence.

People have described to the Royal Commission how their ability to make choices can be limited in large and small ways, affecting where or with whom they live, their intimate relationships, their health care, their education, their work and how they manage their finances. We have also heard about limits to their autonomy in the context of how they participate in the community, their experiences with the justice system and developing plans under the NDIS.

Exercising choice and control and being independent is sometimes confused with being self-reliant and needing no external support. Yet every person, with or without disability, depends on the support of other people and broader social networks. The provision of appropriate support can enable people with disability to maximise their autonomy and independence.

> I hope that this Royal Commission can help people with a disability to have choice and control ... People with disability should have a choice ... they should feel free.[28]

Attitudes towards disability

> Ableism is the foundation of our oppression and consequent suffering ... The deadly bigotry of low expectations and the consequences over a lifetime are killers.[29]

People with disability have told us about the negative or harmful attitudes they often face, as well as assumptions other people make about their quality of life and value to society. They have described how these attitudes can influence their experiences across many areas of life.

Attitudes can contribute to violence against, and abuse, neglect and exploitation of, people with disability. Negative attitudes and unconscious bias can directly or indirectly affect behaviour, and may play a significant role in how people with disability are treated. These attitudes can manifest as unwarranted assumptions about a person's decision-making capacity, low expectations and discrimination. People with disability and their family members have reflected on their experiences of being devalued and stereotyped, as well as of a broad lack of understanding and acceptance of them as equal members of society. This can send a message that people with disability have less value than other members of the community and therefore do not have the same rights as others.

Negative attitudes and beliefs towards disability can intersect with attitudes towards age, gender, gender identity, sexual orientation, ethnicity or race. For example, First Nations people with disability are almost twice as likely to experience discrimination as non-Indigenous people with disability.[30]

Segregation and exclusion

> Negative perceptions, negative judgements and negative expectations are reinforced and become woven into the fabric of our community when the 'other' places for the 'other' people exist.[31]

Segregation is when people with disability are separated from the rest of the community or from settings where people without disability can access supports and services and participate in community and economic life. Historically in Australia, people with disability were segregated in institutions that provided housing, recreation, employment and education – a practice supported by some laws and policies. Although many larger institutions have now closed, some people with disability – particularly people with cognitive disability – remain separated from the wider community in segregated settings.

The Royal Commission has heard about violence against, and abuse, neglect and exploitation of, people with disability across a range of segregated settings, including education, homes and living arrangements, employment and day programs. We have also heard about the negative effect this can have on opportunities to build meaningful and trusted relationships with friends and family.

Exclusion occurs when people are denied access to the social, economic, political and cultural systems that enable a person to be part of the community. The segregation and social exclusion of people with disability produces stigma and discrimination, which may lead to violence, abuse, neglect and exploitation.

First Nations people with disability and culturally and linguistically diverse people with disability may experience intersecting disability discrimination and racism, resulting in segregation, exclusion and isolation. For First Nations people with disability, ongoing intergenerational trauma may contribute to these experiences.

Restrictive practices

> I was forced to take medications not directly tethered to the treatment of my diagnosis but as a tranquilising sedative.[32]

Restrictive practices are interventions or actions that limit the rights or freedom of movement of a person. In Australia, restrictive practices can be used in certain circumstances to prevent or protect people from harm, including perceived harm. They may be used to prevent an individual from expressing what are characterised as ‘behaviours of concern’ for the protection of themselves or others. Restrictive practices include seclusion and the use of restraints, such as physical, chemical, environmental and mechanical restraints.

All states and territories have laws, policies and standards for the use of restrictive practices but there is no uniform regulatory framework across all jurisdictions and settings. We have received information about the use of restrictive practices in educational, residential, health and detention settings, including the use of:

- seclusion and physical and chemical restraints in schools
- physical and environmental restraints in group homes
- physical, chemical and mechanical restraints in health facilities
- seclusion and chemical restraints in detention settings.

Access to services and supports

> Having a good team of support workers who have spent time with me every day and come to understand my disability has been highly beneficial.[33]

Services and supports range from everyday essentials, such as supermarkets, public transport, education and health care, to those that are disability-specific. We have heard how the people who provide or facilitate access to these services and supports, including family members and support workers, can be a source of support and safety and can help prevent and protect people with disability from experiencing violence, abuse, neglect and exploitation. However, we have also heard that sometimes these people can minimise or ignore experiences of violence, abuse, neglect and exploitation when they occur, or be the source of harm.

The Royal Commission has heard about the barriers that people with disability can face when accessing services and supports. These include attitudinal, institutional, environmental and communication barriers. We have also heard about the lack of appropriate services and supports in many places, a problem that can particularly affect First Nations people with disability in remote communities. We have been told about the barriers created by institutional racism towards First Nations people, and that this intersects with disability discrimination. Culturally and linguistically diverse people with disability can encounter particular barriers based on attitudes towards disability and ethnicity, as well as being unable to access information.

Advocacy and representation

> The only strategy I've ever seen capable of making a difference is advocacy and self-advocacy, particularly self-advocacy, empowering people to stick up for themselves.[34]

Advocacy and representation enable people with disability to have their voices heard at all levels of society and to influence issues of deep concern to them. Disability advocacy is acting, speaking or writing to promote, protect and defend the rights of people with disability. Independent advocacy by people with disability plays an important role in implementing and monitoring the *CRPD*.

We have heard from many advocacy and representative organisations that increased advocacy is a key measure to address violence, abuse, neglect and exploitation and would lead to a more inclusive society. We have also heard that there is a lack of advocacy services, including for First Nations people with disability and people with complex needs, and that existing advocacy services are under-funded.

Oversight and complaints

> Put simply, people with a disability who disclose abuse are often not believed.[35]

Oversight and complaints mechanisms help prevent violence against, and abuse, neglect and exploitation of, people with disability, and help ensure appropriate responses when they occur. Each state and territory has primary responsibility for oversight and complaints mechanisms for systems and services in its jurisdiction. Nationally, the NDIS Quality and Safeguards Commission is responsible for the regulation and oversight of services and supports provided for people with disability under the NDIS.

We have been told about difficulties in reporting and complaining in a range of contexts, and that incidents are sometimes minimised, ignored or go unreported. We have also heard that some people with disability have been punished for making complaints about the care or services they receive. Some people with disability described fearing retribution or not being able to access confidential complaints procedures. We have also heard about complaint procedures that are inappropriate for people who are non-verbal or deaf. We have heard that complaints made by people with disability, particularly those with psychosocial or intellectual disabilities, are not always taken seriously or are considered minor. We have been told that reporting and investigation processes are often insufficiently independent and are inaccessible or re-traumatising for the complainant.

Funding

The Royal Commission has heard about the impact of funding on access to support and services for people with disability. Inappropriate funding structures can create disincentives, conflicts of interest and potentially poorer outcomes for people with disability. We have been told that changes to funding models and how funds can be used for supports could lead to more effective protection of people with disability from violence, abuse, neglect and exploitation. Changes of this kind may also encourage reporting and responses to violence, abuse, neglect and exploitation experienced by people with disability.

The Royal Commission will examine these emerging themes through our ongoing work. Our areas of further inquiry are outlined at the end of this Summary.

Key issues

We have heard about key issues across systems and services, including:

- education and learning
- homes and living
- health care
- relationships
- community participation
- economic participation
- the NDIS
- the justice system.

We have also heard about the experiences of people with disability during the COVID-19 pandemic.

The key issues are often connected to the emerging themes we have identified, suggesting that the violence, abuse, neglect and exploitation experienced by people with disability is not limited to discrete settings or contexts. Rather, violence against, and abuse, neglect and exploitation of, people with disability may be the result of systemic failures across multiple areas. We shall explore the association between these failures and the wider exclusion of people with disability from society.

Education and learning

> School was supposed to be a place of feeling safe and supported.[36]

While the Royal Commission has received information about experiences of violence, abuse and neglect across all stages of education, many contributions so far have focused on primary and secondary education. The emerging picture is that not all students with disability in Australia receive the same quality of education as students without disability or have the opportunity to realise their full potential. People have described the long-term impacts of poor education on their employment, health, independence and relationships. What is clear from the information provided to us is the desire for real and lasting improvements to the quality of education for students with disability.

We have heard about the lack of access people with disability have to education and its opportunities and benefits. Many people with disability, their families and advocacy groups describe this as neglect. We have heard about barriers to enrolling in school, limited development opportunities and a lack of reasonable adjustments, supports and planning in the education system. We have also heard about the exclusions experienced by students with disability, including the disproportionate use of suspensions and expulsions. We have been told how restrictions related to COVID-19 have exacerbated existing barriers to education or created new ones for students with disability.

We have heard about physical, verbal and emotional violence and abuse in educational settings, including restrictive practices being used on students with disability and schools asking parents to medicate their children to address behaviours of concern.

People and organisations have also described what they see as the key factors for safe, inclusive and quality education, including:

- strong leadership
- inclusive culture
- effective workforce training
- collaboration between students, parents and educators
- accessibility
- provision of adjustments and supports
- increased disability awareness and acceptance.

We have heard different perspectives about the best way to structure Australia’s education system for students with disability.

Some students with disability are educated in 'separate environments designed or used to respond to a particular or various impairments, in isolation from students without disabilities'.[37] The United Nations Committee on the Rights of Persons with Disabilities refers to this as 'segregation'. In Australia, schools, classes or units for students with disability are often called 'special' schools, classes or units. All state and territory education systems include special/segregated education settings as a parallel or dual system. We have heard from some parents of students with disability, educators and associations representing special education that special/segregated education settings can differentiate education, adapt curriculum, provide specialist support and cater to diverse needs.

We have also heard different views from those who endorse inclusive education, including some people with disability, parents of students with disability, educators, peak organisations, and academics. Many have told us they believe there is a link between special/segregated education settings and higher rates of violence, abuse and neglect in these settings and in later life. Some organisations and academics describe these settings as based on an understanding of disability as deficit. Organisations have also told us this perpetuates the exclusion of people with disability and that once a student is placed in a special/segregated school, class or unit, they rarely transition into 'mainstream' education or into mainstream work.

Public hearing 2: Inclusive education in Queensland – preliminary inquiry

Public hearing 2 was the first of our hearings to examine violence against, and abuse, neglect and exploitation of, people with disability in educational settings.

Its main purpose was to undertake an initial examination of some of the systemic issues, challenges and barriers that can prevent students with disability from obtaining a safe, inclusive and high quality education.

The Royal Commission heard evidence about the education system in Queensland, as well as interstate, at public and private schools. It explored the experiences of students with disability and related policies and procedures.

The Royal Commission heard evidence from 14 witnesses, including parents of students with disability, representatives from advocacy organisations, academic experts, the president of the Queensland Teachers' Union, and staff of the Queensland Department of Education.

Education is important to the life journey of people with disability and adverse experiences at school can have significant pervasive effects on a person's life. The right to education belongs to everyone as a human right under international law. The *CRPD* provides that States Parties recognise the right of people with disability to education 'without discrimination and on the basis of equal opportunity'.[38]

The evidence from the public hearing indicates that there are several key drivers and forms of violence, abuse, neglect and exploitation in the context of the education of children with disability. These include:

- ‘gatekeeping’ practices (where people and organisations put barriers in place to stop students with disability engaging in mainstream services)
- mistreatment of students with disability by school staff and other students, including bullying and harassment
- the use of restrictive practices against students with disability, including physical restraint, chemical restraint and seclusion, such as when students are left alone and without educational materials as a method of occupying time or in response to behaviours of concern
- a lack of adjustments, supports and individualised planning that students with disability need to have proper access to education and participate in school life
- low expectations of students with disability and student outcomes, and how school staff exclude students with disability from activities as they expect they would not be able to participate
- the misuse of disciplinary measures, including suspensions and exclusions, in response to behaviours of concern, which can occur where school staff struggle to understand the nature and manifestations of the student’s disability
- poor communication and collaboration between school staff and students with disability and their parents, which may lead to neglect, compared to the role of positive relationships in providing safe, inclusive and quality education
- poor complaint processes and responses to complaints about a student’s educational experience, which can place the continued enrolment of the student with disability at risk or potentially damage the relationship between parent and teacher
- the impact of joint funding arrangements between the Australian Government and state governments and the different data collection requirements of each, which can be time consuming, onerous and inconsistent
- workforce capability, including inadequate initial and continuing teacher training and education.

Chapter 12 provides an overview of the evidence gathered during Public hearing 2 and outlines the areas for further inquiry arising from that evidence (which are also summarised in ‘Areas of further inquiry’ at the end of this Summary). A detailed report of Public hearing 2 is available on the Royal Commission website.

Homes and living

> She was hit, pushed, spat upon and had her property constantly stolen both by workers and other co-tenants.[39]

Everyone has the right to feel safe at home. A person's home is central to their independence and wellbeing. Yet people with disability are more likely to feel unsafe in their homes than people without disability. In Australia, most people with disability live in private homes, with a relatively small proportion residing in supported accommodation, including group homes, boarding houses and residential institutions. Some people with disability live in short-term accommodation or experience unstable housing or homelessness. Our early work has focused on group homes, but we have heard about violence, abuse, neglect and exploitation occurring across the range of residential settings.

We have heard about people with disability being subjected to violence, abuse, neglect and exploitation in private homes. We have been told about some people with disability having unexplained injuries and experiencing neglect in supported accommodation. We have also heard about the barriers to independent living that people with disability can face, including attitudinal barriers and a lack of affordable and accessible housing options, which particularly affect First Nations people and people from rural and remote communities.

Despite the trend towards deinstitutionalisation, which began in the 1960s and resulted in many larger institutions closing by the 1980s, we have heard that newer facilities such as group homes can emulate the institutional cultures and practices typical in larger institutions.

Public hearing 3: The experience of living in a group home for people with disability

Public hearing 3 inquired into the experiences of people with disability living in group homes. We were particularly concerned to examine whether living in a group home heightens the risk of violence, abuse, neglect or exploitation for people with disability.

The Royal Commission decided to undertake this inquiry in an early public hearing because a person's home is the place where they should feel and be safe and secure. A home is central to a person's life, dignity, independence and wellbeing.

The Royal Commission heard evidence from 28 witnesses, including people with disability who had direct experience of living in group homes or other forms of supported accommodation. They described being deprived of choice in shared supported accommodation, leading to a loss of control and autonomy and exclusion from social, economic and cultural life.

We heard evidence that lack of choice can also lead to residents of group homes or other supported accommodation being exposed to violence, abuse, neglect and exploitation.

The key themes emerging from the hearing include:

- the consequences of deinstitutionalisation, including the emergence of the group homes model and the unintended consequences flowing from that model
- autonomy for people with disability, including having choice and control over where and with whom they live, choice of service provider, and individualised service delivery within their group home
- safety in group homes being undermined by the 'casualisation' of staff, poor training of disability support workers and a punitive culture among staff
- safety strategies, such as developing networks and trusted relationships with a range of people outside of the closed environment as well as independent advocacy and self-advocacy
- the critical importance of reporting violence, abuse, neglect and exploitation to ensure effective responses and the limits of compliance-based approaches to assessing the quality and safety of a service
- the importance of support for transitioning to alternatives to living in a group home
- redress for survivors of violence, abuse, neglect and exploitation in connection with the provision of disability services.

Chapter 13 provides an overview of the evidence gathered during Public hearing 3 and outlines the areas for further inquiry arising from that evidence (which are also summarised in 'Areas of further inquiry' at the end of this Summary). A detailed report of Public hearing 3 is available on the Royal Commission website.

Health

People with disability experience poorer health than people without disability. People with disability and their families have told us about their experiences accessing health care and the challenges they can face getting the care they need. We have also heard about violence and abuse in health care settings and of people with disability experiencing involuntary treatment and diagnostic overshadowing (when symptoms of physical or mental health conditions are misattributed to a person's disability).

We have heard about the range of barriers that people with disability face when accessing health care. While high quality health care is provided to some people with disability, we have also been told about health staff who appeared reluctant to provide people with disability with appropriate care. This was attributed to perceptions about the value of people with disability, people with disability being regarded as difficult and time-consuming, or financial disincentives to devoting the time necessary to treat people with disability. We have also heard about health staff not listening to patients with disability, or talking about them rather than to them.

We have been told that people with disability have faced difficulties accessing health care during the COVID-19 pandemic. Many people and services rely on face-to-face contact. As a result, we have heard that many people with disability have not been able to access health care, despite increased provision of telehealth services. There have also been challenges accessing COVID-19 testing facilities and personal protective equipment.

We have heard that diagnostic overshadowing can result in delayed or incorrect diagnoses of medical issues. The intersection of disability discrimination and racism can result in serious medical issues being ignored for First Nations people with disability.

Some people with disability have told us about receiving involuntary medical treatment and the effect this has had on them. For example, we have heard about:

- electroconvulsive therapy used against a person's will
- medication used without consultation or informed consent
- police being used to enforce involuntary treatment
- chemical sedation without therapeutic benefit
- seclusion and physical restraint being used to manage mental health
- threats of involuntary treatment orders if people question medical professionals.

We have also heard that some women with disability in group homes are subjected to forced contraception.

Public hearing 4: Health care and services for people with cognitive disability

Public hearing 4 was the first of our hearings to inquire into health issues for people with disability.

The purpose of the hearing was to examine the health care and services provided to people with cognitive disability in Australia and to determine whether this group of people is subjected to systemic neglect. The Royal Commission acknowledges that the quality of health care provided varies and there are examples of excellent care. However, the evidence warrants finding that there has been, and continues to be, systemic neglect of people with cognitive disability in the Australian health system.

The Royal Commission heard evidence from 38 witnesses, including people with cognitive disability, their parents, siblings and supporters, as well as advocates, experts, medical professionals and representatives of government departments and agencies.

The evidence at the hearing included first-hand accounts from people with cognitive disability and their families about their experiences in the health system, what quality health care looks like for them, and the barriers to quality health care that they have faced.

Key themes from the hearing include the:

- critical role that a person-centred approach, trusting relationships with health professionals, and collaborative planning of care and treatment play in ensuring quality health care for people with cognitive disability
- influence of pervasive societal attitudes towards people with cognitive disability on decision-making concerning health care and treatment
- importance of communication and information sharing, including health professionals communicating directly with people with cognitive disability and their parents or supporters, as well as between health services and health professionals
- importance of strong advocacy in ensuring people with cognitive disability are provided with quality health care
- systemic challenges that exist in the health system, particularly:
    - providing health care over a person’s lifetime, including preventative health care, dental health care, the transition from paediatric to adult health care, mental health care and end-of-life care
    - for First Nations people with disability
    - for people in non-metropolitan areas

- need to better integrate the health and disability service sectors
- trauma and distress that can be associated with health procedures and treatment for people with cognitive disability, which can accumulate and have implications for all aspects of a person's life
- need for better education and training to improve knowledge and attitudes of health professionals and their skills in communicating with people with cognitive disability and their families
- importance of data collection and research into the health of people with cognitive disability.

The hearing also examined Australian Government and New South Wales Government initiatives to improve health care for people with disability, including the National Roundtable and draft National Roadmap for improving the health of Australians with intellectual disability.

Chapter 14 provides an overview of the evidence gathered during Public hearing 4 and outlines the areas for further inquiry arising from that evidence (which are also summarised in 'Areas of further inquiry' at the end of this Summary). A detailed report of Public hearing 4 is available on the Royal Commission website.

Relationships

Everyone has a right to family and a right to be free from violence, abuse, neglect and exploitation in their relationships. The Royal Commission has received information about people with disability being subjected to domestic and family violence, sexual violence, child removal and child relinquishment. Many people who have shared their stories with us have told us of experiencing multiple forms of violence and abuse in their relationships.

People with disability experience higher rates of domestic and family violence than people without disability. People with disability can experience particular forms of domestic and family violence, including the withholding of food, water, medication or support services, the use of restraints, reproductive control and forced isolation. We are also hearing about violence or abuse by other family or kinship network members and support workers.

Women with disability experience much higher rates of violence by a current or previous partner than women without disability, as do men with disability compared with men without disability. The same pattern exists for sexual violence experienced by women with disability compared with women without disability, and men with disability compared with men without disability.

We have heard that during the COVID-19 pandemic, people with disability experienced increased isolation because of restrictions on movement and close physical contact. This may mean that people with disability have had less access to support networks and been less able to report and escape domestic and family violence.

The Royal Commission has also received information about circumstances where children have been removed from a parent or parents with disability. We have heard from adults with disability about being removed from their families when they were children. We have heard about these experiences for First Nations families in the context of historical and current practices of child removal. We have been told that these experiences are, in part, responsible for widespread mistrust of mainstream systems by First Nations families, resulting in families being less likely to access mainstream supports and services.

Community participation

Participating in the community is about the relationships we form, our engagement in civic life and our sense of belonging. People with disability continue to confront barriers that prevent their full and equal participation in the community. These barriers are attitudinal, institutional, environmental and communicative.

Accessibility is essential for people with disability to live independently and fully participate in society on an equal basis with others. People with disability are excluded when buildings, public and private spaces and information are not accessible to them. Some people with cognitive disability discuss their experiences of safety in terms of the physical environment, such as using public transport or negotiating hazards in public areas. Some Deaf people associate safety with access to information. People with disability have also told us they often encounter physical barriers to accessing building and environments, and that these barriers are only the 'tip of the iceberg' for how they are excluded from society.[40]

We have heard how access to information was unreliable and confusing during the COVID-19 pandemic and that many people with disability feel that they have been overlooked or left behind during the crisis. For some people, it has not been possible to follow social distancing restrictions and they fear increasing social isolation after the pandemic.

Economic participation

People with disability experience high levels of socio-economic disadvantage and are more likely than people without disability to experience poverty, financial hardship and unemployment, with lower incomes and higher costs associated with living with disability.

People with disability have told us about their experiences of violence and abuse in open and in segregated employment. They have described being physically, verbally and sexually abused by colleagues and managers in the workplace. This includes experiences of violence and abuse in some Australian Disability Enterprises (ADEs), or 'sheltered workshops'. We have heard that in some instances, when these issues have been raised with ADE service providers, they have been ignored or not addressed. We have also heard about the lack of meaningful work in ADEs and of poor workplace conditions, as well as of difficulties in transitioning to open employment.

> We keep talking about how different these people are, we laugh at them, we mock them, we continually talk about what they can't do. We put them in low paid, hard factory jobs and we pay them in coins. For the whole of their life they have been put down and kept in sheltered workshops.[41]

Australian governments have many policies and programs related to the economic participation and employment of people with disability. Despite government investment in rehabilitation and employment-related services, labour force participation rates for people with disability have remained largely unchanged over the past two decades. A number of people with disability have described not being able to find work, experiencing discrimination in the workplace or lacking access to opportunities for career progression.

We have also been told about productivity-based wages resulting in wage inequity for some people with disability.

We have also heard about the socio-economic effects of the COVID-19 pandemic on people with disability. The Australian Government introduced two coronavirus supplement payments for eligible households and individuals to manage the economic impact of the pandemic. The exclusion of people receiving the Disability Support Pension from the supplement payments adversely affected some people with disability.

National Disability Insurance Scheme (NDIS)

Our terms of reference direct us to consider the quality and safety of services, including those provided by the NDIS under the NDIS Quality and Safeguarding Framework.[42] The NDIS is a major reform of social policy in Australia, replacing nine Australian, state and territory systems for funding supports and services for people with disability.

What we have heard so far includes acknowledgement of some improvements under the NDIS, but also frustration, dissatisfaction and anger that many of the intended benefits are yet to be realised.

Justice

The Royal Commission has heard that people with disability are over-represented in the criminal justice system and they often face a range of barriers to accessing services and supports needed to protect their rights and interests. The barriers include:

- a lack of awareness of legal rights
- the failure of those working in the system to recognise that people have a disability and to respond appropriately
- the difficulty faced by people with disability in negotiating an unfamiliar and often hostile system.

Many people with disability regularly come into contact with the justice system throughout their lives, whether as a victim of crime, as a person accused of committing an offence or as a witness.

We have been told about a range of experiences that people with disability have had with police. These include being disbelieved when they have tried to report violence and abuse and being treated as the offender, rather than the complainant. We have also been told about instances where people with disability have been approached by police or formally questioned when they believe they should not have been.

People with cognitive or psychosocial disability are at higher risk of moving in and out of the justice system through repeated short-term prison sentences. We have also heard that people with cognitive or psychosocial disability are disproportionately subject to indefinite detention orders, which can mean they are held for a longer period than if they had been convicted. We have been told that repeated incarceration and indefinite detention are linked to inadequate support for people with complex needs when they are outside custodial settings.

People with disability may be at heightened risk of violence, abuse, neglect and exploitation in closed environments. Some people have raised concerns about the use of restrictive practices on people with cognitive disability and the use of solitary confinement to ‘manage’ people with disability.

People with disability also come in contact with the civil justice system. For example, we have been told that guardianship and administration orders – which authorise a person to make decisions on another person’s behalf – can limit people’s choice and control. These orders can have the unintended consequence of leading to violence against, and abuse, neglect and exploitation of, people with disability, particularly financial exploitation. On the other hand we have been told that guardianship orders may be put in place in response to violence, abuse, neglect and exploitation and that they can act as a mechanism to prevent abuses, such as forced medical treatment.

The Royal Commission will examine these key issues through our ongoing work. Our areas of further inquiry are outlined at the end of this Summary.

First Nations people with disability

Disability in Australia can be traced back 20,000 years to the footprint of a one-legged Aboriginal man who used a walking aid to participate in a group hunt near Lake Mungo in New South Wales. His footprint shows that First Nations people with disability were active participants in community life.[43] It is also symbolic of the inclusion that people with disability seek to achieve in Australia today.

Our terms of reference direct us to have regard to the particular situation of First Nations people with disability.[44] As a population made up of distinct Aboriginal and Torres Strait Islander groups, there is significant diversity among First Nations people, including those with disability.

Our work is informed by the human rights standards relevant to First Nations peoples as a distinct cultural group, as well as their rights as people with disability. Along with the *CRPD*, the Royal Commission is guided by the *United Nations Declaration on the Rights of Indigenous Peoples* (*UNDRIP*), which Australia formally endorsed in 2009.[45]

As First Nations people with disability start to share their experiences of violence, abuse, neglect and exploitation with us, we are seeing the human stories behind the numbers. What is emerging is a complex picture that suggests First Nations people with disability face multiple barriers to their safety, wellbeing and inclusion in Australian society and experience many different forms of violence, abuse, neglect and exploitation.

The Royal Commission has targeted engagement with First Nations people with disability, guided by our First Nations engagement principles. These 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. The First Nations Peoples Strategic Advisory Group provides advice and leadership on matters relating to First Nations people with disability. Throughout these engagements we heard of experiences that highlight the disproportionate challenges faced by First Nations people with disability.

Concepts of disability in First Nations communities

> 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'. 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.[46]

First Nations people with disability have told us that their understanding and experiences of disability differ to those of the general population. While there is no comparable term for 'disability' in many traditional languages, there are words that describe what people see, and these words describe different types of conditions, such as blindness and hearing loss.

We have been told that there may be a reluctance among some First Nations people to identify with the label of 'disability'. This can be due to a lack of awareness, shame, stigma or issues with accessing supports. Organisations such as the First Peoples Disability Network Australia (FPDN) suggest that the number of First Nations people with disability is likely to be substantially higher than the figures reported in official data.

First Nations people with disability have identified the importance of understanding health as more than just the absence of disease or pain, and that health encompasses mental, cultural, spiritual and physical health and wellbeing. These sentiments inform thinking on disability, which is a relatively new conversation within some First Nations communities. The approach to disability is often expressed in a way that acknowledges the individual and what they are capable of, as opposed to their limitations, labels or medical diagnosis.

‘Double discrimination’ of First Nations people with disability

> … 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.[47]

First Nations people with disability face ‘double discrimination’ owing to their dual status of being Indigenous and a person with disability. This is compounded by the ongoing effects of factors such as colonisation, intergenerational trauma, poverty and chronic health issues. We know that First Nations people with disability are more likely to experience harm than the general population. They are more likely to have:

- experienced threats of physical violence
- been removed or had relatives removed from their family
- experienced high or very high levels of psychological distress
- been detained due to behaviours associated with a cognitive disability, fetal alcohol syndrome or other disability.

Despite the heightened risk of harm and the number of people with disability in the First Nations population, the experiences of First Nations people with disability have a relatively low profile in national policy discussions. There is, for example, no First Nations community-controlled disability sector. The lack of culturally appropriate services and supports available for First Nations people with disability has emerged as an important theme in our work. It is in this context the Royal Commission acknowledges persistent calls by the FPDN and others to elevate discussions about disability, including through a First Nations disability sector.

We recognise the role of self-determination in addressing the barriers facing First Nations people with disability. First Nations people with disability have told us that to achieve real and lasting change they must be involved in decision-making that affects them. We have encouraged and continue to encourage First Nations people to share their experiences with us by making submissions, responding to our issues papers, participating in private sessions and giving evidence at public hearings.

We look forward to continuing to engage and work with First Nations people with disability, their families and support organisations to tell a more complete story of what it means to be a First Nations person with disability in this country.

> It is the unwritten chapter in our history of Australia and also in the First Nations rights movement history. We don't have that chapter written ... We know it must be written and this is an opportunity for First Nations peoples to have their voice, and voice their truth about what has been happening today.[48]
>
> Andrea Mason OAM,
> Ngaanyatjarra and Karonie woman and Commissioner

Culturally and linguistically diverse people with disability

Our terms of reference direct us to have regard to the particular situation of culturally and linguistically diverse people with disability.[49] As discussed earlier, there is no agreed definition of 'culturally and linguistically diverse'. There is also no reliable data available on violence against, and abuse, neglect and exploitation of, culturally and linguistically diverse people with disability in Australia.

The Australian community includes people with disability from many different cultural backgrounds and who speak many different languages. Australian Bureau of Statistics data shows that the most commonly spoken languages for people with disability who do not speak English at home are Italian, Greek and Arabic, followed by Vietnamese, Mandarin and Cantonese.[50]

Some culturally and linguistically diverse people with disability are from communities that have been established in Australia for generations. Other people with disability are from new and emerging communities, including migrants and refugees who have recently arrived in Australia.[51] The barriers and challenges faced by people with disability in those communities are likely to be different from those faced by people with disability in other communities.

The Royal Commission has developed culturally and linguistically diverse engagement principles to help ensure our engagement with culturally and linguistically diverse people with disability is inclusive and culturally appropriate.

We are in the early stages of our work with people with disability from culturally and linguistically diverse communities. Nonetheless, we have engaged with culturally and linguistically diverse people, community leaders, advocates and organisations in all states and territories and have started to hear about the barriers and challenges they face. Our understanding of the critical issues for these communities is still developing and will be developed further as the Royal Commission proceeds.

Our future direction

> ... the most important part of the Royal Commission's work is our engagement with people with disability, their families and supporters. Your contributions will be the heart and soul of this Royal Commission. You are the key to its success.[52]
>
> The Hon Ronald Sackville AO QC, Chair

The Royal Commission is well progressed in examining the issues set out in our terms of reference. Many people and organisations have shared their experiences and expertise and provided thoughtful and useful information during the first 15 months of our inquiry. However, there is still much to do.

The Royal Commission will continue its inquiry through public hearings, our research program, and policy work. We will continue to listen to the experiences of people with disability, their families and supporters through private sessions, submissions and community engagement.

We will continue our efforts to engage with the groups of people identified in our terms of reference, including First Nations people with disability and people with disability from culturally and linguistically diverse communities. We will also investigate the multi-layered experiences of people with disability based on their age, sex, gender, gender identity, sexual orientation and intersex status, including by engaging with people with disability from the LGBTIQ+ community.

The Royal Commission will also explore what needs to be done to create a more inclusive society, where people with disability are accepted and valued, and where their independence and right to live free from violence, abuse, neglect and exploitation are upheld.

The information and evidence we gather will inform the recommendations we make for reform. The Royal Commission is committed to identifying opportunities to support all people with disability to live fuller, safer, more inclusive lives, now and in the future.

However, this Royal Commission alone cannot bring about transformational changes. It will be up to governments, institutions and the community to embrace the call for change and implement our recommendations.

> My hope for future is that people with disabilities are valued in the community & genuinely treated equally.[53]

Areas of further inquiry

Through our work so far, the Royal Commission has identified a number of areas that warrant further inquiry. These include those arising from evidence at our first three public hearings, proposed measures to address gaps in data and the themes and issues emerging through submissions, responses to issues papers and engagement with the disability community.

Our inquiry will include a particular focus on the experiences of First Nations people with disability and culturally and linguistically diverse people with disability.

The Royal Commission will examine the areas for further inquiry outlined below through our ongoing work.

Public hearings

Public hearing 2: Inclusive education in Queensland – preliminary inquiry

Areas for further inquiry related to Public hearing 2 include:

- gatekeeping practices and the denial or informal discouragement of students with disability from attending the schools or educational settings of their or their families' choice, factors that contribute to gatekeeping and the connection this may have to educational neglect
- the causes of mistreatment of students with disability in schools by school staff and students, as well as factors that protect against and measures that can prevent such conduct
- the use of restrictive practices in Australian schools, and the means by which the improper use of such practices can be prevented, including through clear policy and practice guidance, training, record keeping and improved data collection, and effective and efficient complaints processes
- factors that lead to adjustments, supports and individualised planning not being identified or implemented, and the resourcing needed to provide proper adjustments, supports and individualised planning
- why some educators and educational environments may have or create low expectations of students with disability, and measures that can be taken to counter this culture
- the misuse of disciplinary measures in response to behaviours of concern, including data on suspensions and expulsions, and factors that contribute to the use of suspension and expulsion rather than other, appropriate measures for dealing with behaviours of concern
- relationships, communication and collaboration between school staff, students with disability and their parents, and links to violence against, and abuse, neglect and exploitation of, students with disability
- the operation of oversight and complaints mechanisms in educational settings

- funding arrangements and what measures can be taken to streamline access to funding and resources, and best practice funding models for schools to support students with disability, including co-teaching models and those that use para-professionals alongside teachers
- teacher education and training, both pre- and post-qualification, and the extent to which it adequately prepares teachers to educate and support students with disability
- existing data collection models and how to address gaps
- the experiences of First Nations students with disability and culturally and linguistically diverse students with disability
- inclusive education, including measures to encourage more effective programs of inclusive education in mainstream schools.

These are discussed further in Chapter 12.

Public hearing 3: The experience of living in a group home for people with disability

Areas for further inquiry related to Public hearing 3 include:

- potential reform of laws, policies and practices that will enable people with disability who reside in group homes or other forms of supported accommodation to exercise and enjoy their right to autonomy
- measures that could improve the culture of providers of accommodation and disability services with the aim of eliminating, so far as possible, violence against, or abuse, neglect and exploitation of, people with disability residing in group homes or other supported accommodation
- how disability support workers in group homes and other forms of supported accommodation can better meet the needs and wishes of the people with disability they support, including considering qualifications and experience of support staff
- how the safety of people with disability living in group homes or other supported accommodation can be enhanced
- alternatives to group homes for people with disability
- the forms of redress available to people with disability who are subjected to violence, abuse, neglect or exploitation while residing in group homes or supported accommodation, and measures that should be taken to ensure that people in those circumstances receive independent advice and support to enable them to pursue the remedies available to them.

These are discussed further in Chapter 13.

Public hearing 4: Health care and services for people with cognitive disability

Areas for further inquiry related to Public hearing 4 include:

- measures needed to enable people with cognitive disability, where possible, to make informed decisions about their care and treatment and to exercise choice and control in their interactions with the health system
- the ways in which negative attitudes towards people with cognitive disability within the health system reflect outcomes and inflict distress
- means of improving communication between both health professionals and the person with cognitive disability, their parents or supporters, and between health professionals and health services – including by requesting health departments review their policies, practices and information to identify actions that will make these more readily accessible and understood
- the particular barriers limiting the access of people with cognitive disability living in regional, rural or remote areas to adequate health care, and measures to overcome those barriers
- the multiple forms of disadvantage experienced by First Nations people with cognitive disability and the barriers to adequate health care they face, and culturally appropriate measures to improve access to health services for First Nations people with cognitive disability
- the means by which people with cognitive disability, their families, carers and supporters can be supported in advocating for health care and treatment, including support for independent advocacy and self-advocacy
- measures to improve preventative health, oral health, transition to adult health care, mental health and palliative care for people with cognitive disability
- integration of health and disability services, including the practices and systems adopted in closed settings such as group homes that may limit people with cognitive disability from accessing appropriate health care
- adjustments that should be made to the hospital and clinical environment and to clinical procedures to minimise distress for people with cognitive disability when consulting health professionals, undergoing tests, receiving treatment or being admitted to hospitals
- how training and education of health professionals can result in better quality health care and outcomes for people with cognitive disability
- measures to improve the collection, analysis and publication of data, including for use in research into the health of people with cognitive disability
- other initiatives to improve health care for people with cognitive disability.

These are discussed further in Chapter 14.

Data

The nature and extent of violence against, and abuse, neglect and exploitation of, people with disability is discussed in Chapter 15, which also outlines the areas that the Royal Commission will examine further to overcome data gaps. These include:

- examining the adequacy of the NDIS Quality and Safeguards Commission's data collection, monitoring and reporting systems for upholding the rights and promoting the health, safety and wellbeing of people with disability
- obtaining information about the barriers to widespread implementation of standard questions to identify people with disability in governments' and organisations' databases
- obtaining information about how the National Disability Data Asset can be used to effectively monitor violence against, and abuse, neglect and exploitation of, people with disability
- inquiring into the plans of governments, service providers and others for publishing data in a way that shows results separately for people with and without disability and, where possible, separately for First Nations people with disability and non-Indigenous people with disability
- exploring how to collect data on experiences of violence, abuse, neglect and exploitation from groups of people who are currently not included in existing surveys
- obtaining information about why previous recommendations to improve data collection have not been implemented to better understand the barriers to implementation.

Emerging themes and key issues

Emerging themes and key issues are discussed in Chapter 17, which also provides an overview of the areas that the Royal Commission will examine further. These include:

- the links between limits on choice and control across all settings and contexts, and the violence, abuse, neglect and exploitation experienced by people with disability
- how attitudes towards disability may influence violence against, and abuse, neglect and exploitation of, people with disability
- the impact of segregation and exclusion on the lives of people with disability
- the impact of restrictive practices on people with disability and the rules and safeguards that should apply to prevent their unwarranted use
- the role of families, supporters and advocates in preventing violence against, and abuse, neglect and exploitation of, people with disability
- oversight and complaint mechanisms
- funding structures and the impacts these can have on access to services and supports

- the nature and extent of violence against, and abuse, neglect and exploitation of, people with disability in all settings and contexts throughout their lives
- measures required to ensure students with disability receive a safe, inclusive and quality education, in addition to the areas for further inquiry arising out of Public hearing 2
- how homes and living arrangements can support the independence of people with disability and their right to live free from violence, abuse, neglect and exploitation, in addition to the areas for further inquiry arising out of Public hearing 3
- changes necessary to achieve access to quality health care for people with disability, in addition to the areas for further inquiry arising out of Public hearing 4
- how to prevent people with disability from experiencing violence, abuse, neglect and exploitation in the context of relationships
- how to address barriers to parenting experienced by people with disability
- how community participation can contribute to a more inclusive society and support the independence of people with disability
- the connection between poverty, unemployment and underemployment and violence against, and abuse, neglect, and exploitation of, people with disability, as well as the effectiveness of employment policies and programs for people with disability
- the experiences of people with disability in the justice system, including access to justice and guardianship and administration orders.

During the course of this Royal Commission, we may identify additional areas for inquiry as we gather further evidence and information.

The information and evidence we gather will inform the recommendations we will make in order to promote a more inclusive society that supports the right of people with disability to live free from violence, abuse, neglect and exploitation.

Endnotes

1 Transcript, Sam Petersen, Public hearing 3, 6 December 2019, P-439 [14–15].

2 *Letters Patent* (Cth), 4 April 2019 amended 13 September 2019, (r).

3 *Letters Patent* (Cth), 4 April 2019 amended 13 September 2019, (s).

4 *Letters Patent* (Cth), 4 April 2019 amended 13 September 2019. Each state government in Australia has also issued letters patent establishing the Royal Commission under state legislation. These letters patent are in substantially the same terms as those issued by the Commonwealth and are available on the Royal Commission website.

5 *Letters Patent* (Cth), 4 April 2019 amended 13 September 2019, (a) (b).

6 *Letters Patent* (Cth), 4 April 2019 amended 13 September 2019, (c).

7 *Letters Patent* (Cth), 4 April 2019 amended 13 September 2019, (g).

8 *Letters Patent* (Cth), 4 April 2019 amended 13 September 2019, (a).

9 *Letters Patent* (Cth), 4 April 2019 amended 13 September 2019, recitals.

10 Intersectionality describes the unique discrimination that arises from the interaction of ableism with other forms of oppression such as racism, sexism, ageism or homophobia.

11 ABC Four Corners, *In our care*, 24 November 2014. <www.abc.net.au/4corners/in-our-care/5916148>

12 Australian Bureau of Statistics, *Disability, Ageing and Carers, Australia: Summary of findings, 2018,* Catalogue number 4430, 24 October 2019.

13 Australian Bureau of Statistics, *Disability, Ageing and Carers, Australia: Summary of Findings, 2018,* Catalogue number 4430, 24 October 2019.

14 Australian Bureau of Statistics, *Disability, Ageing and Carers, Australia: Summary of Findings, 2018,* Catalogue number 4430, 24 October 2019, Table 3.1.

15 Australian Bureau of Statistics, *Disability, Ageing and Carers, Australia: Summary of Findings, 2018,* Catalogue number 4430, 24 October 2019, Table 1.1.

16 Australian Bureau of Statistics, *National Aboriginal and Torres Strait Islander Health Survey, 2018–19*, Catalogue number 4715, 26 May 2020, Table 2.1 and Table 2.3.

17 Australian Bureau of Statistics, *National Aboriginal and Torres Strait Islander Health Survey, 2018–19*, Catalogue number 4715, 11 December 2019. Results accessed using Australian Bureau of Statistics Table Builder Age of person 0–17, then 18 plus; by Disability status.

18 Australian Bureau of Statistics, *Disability, Ageing and Carers, Australia: Summary of Findings, 2018,* Catalogue number 4430, 24 October 2019. Results accessed using Australian Bureau of Statistics Table Builder Disability status by Whether has a disability and Country of birth (broad groupings) and Main language spoken at home (broad groupings) and Proficiency in spoken English. Numbers have been rounded and likely under-estimate the true prevalence of disability for people who do not speak English well or at all.

19 Georgina Sutherland, Anne Kavanagh, Gwynnyth Llewellyn, Sean Byars, Lauren Krnjacki and Jen Hargrave, *Nature and extent of violence, abuse, neglect and exploitation against people with disability in Australia*, Report prepared for the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, March 2020, p 7.

20 Australian Bureau of Statistics, *National Aboriginal and Torres Strait Islander Health Survey, 2018–19*, Catalogue number 4715, 11 December 2019. Results accessed through Australian Bureau of Statistics Table Builder, Age of person 0-17, then 18 plus; by Disability status; by Whether experienced physical harm in last 12 months.

21 Georgina Sutherland, Anne Kavanagh, Gwynnyth Llewellyn, Sean Byars, Lauren Krnjacki and Jen Hargrave, *Nature and extent of violence, abuse, neglect and exploitation against people with disability in Australia*, Report prepared for the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, March 2020, p 3.

22 Name withheld, Submission in response to *Rights and attitudes issues paper*, 2 May 2020.

23 *Letters Patent* (Cth), 4 April 2019 amended 13 September 2019.

24 *Convention on the Rights of Persons with Disabilities*, opened for signature 30 March 2007, 999 UNTS 3 (entered into force 3 May 2008).

25 *Convention on the Rights of Persons with Disabilities*, opened for signature 30 March 2007, 999 UNTS 3 (entered into force 3 May 2008), preamble.

26 *Letters Patent* (Cth), 4 April 2019 amended 13 September 2019, (g).

27 This interim report is based on the Royal Commission's work from 5 April 2019 to 31 July 2020.

28 Transcript, Jane Rosengrave, Public hearing 3, 2 December 2019, P-64 [32–33], P-65 [1–13]; Exhibit 3-20, Statement of Jane Rosengrave, 28 November 2019, at [28].

29 Glenda Lee, Royal Commission community forum, November, 2019.

30 Australian Bureau of Statistics, *Disability, Ageing and Carers, Australia: Summary of Findings, 2015*, Catalogue number 4430.0, 20 April 2017.

31 Jane Sherwin, Submission in response to *Rights and attitudes issues paper*, 10 June 2020, ISS.001.00211_01, p 2.

32 Name withheld, Submission, 6 November 2019.

33 Transcript, Peter Gibilisco, Public hearing 3, 2 December 2019, P-24 [16–18].

34 Transcript, Kevin Stone, Public hearing 3, 4 December 2019, P-167 [19–21].

35 Sexual Assault Support Service, Submission in response to *Criminal justice system issues paper*, 4 April 2020, ISS.001.00108, p 5.

36 Craig Maynard, Submission, 11 September 2019.

37 Committee on the Rights of Persons with Disabilities, *General comment No 4 (2016) on the right to inclusive education*, UN Doc CRPD/C/GC/4 (2 September 2016) [11].

38 *Convention on the Rights of Persons with Disabilities*, opened for signature 30 March 2007, 999 UNTS 3 (entered into force 3 May 2008), art 24.

39 Name withheld, Submission in response to *Group homes issues paper*, 3 March 2020.

40 Speaker (name withheld), Royal Commission community forum, February 2020.

41 Peter Carmichael, Submission, 26 April 2020.

42 *Letters Patent* (Cth), 4 April 2019 amended 13 September 2019, (f).

43 Scott Avery, *Culture is inclusion: A narrative of Aboriginal and Torres Strait Islander people with disability*, First Peoples Disability Network Australia, 2018, p 2.

44 *Letters Patent* (Cth), 4 April 2019 amended 13 September 2019 (g).

45 *United Nations Declaration on the Rights of Indigenous Peoples*, GA Res 61/295, UN Doc A/RES/61/295 (2 October 2007, adopted 13 September 2007).

46 Damian Griffis, 'Disability in Indigenous communities; addressing the disadvantage', *ABC Ramp Up*, 20 April 2012. <www.abc.net.au/rampup/articles/2012/04/20/3481394.htm>

47 Speaker (name withheld), Royal Commission workshop, Sydney, August 2019.

48 Racheal Knowles, 'Andrea Mason OAM to write unwritten chapter of First Nations disability in Royal Commission', *National Indigenous Times*, 7 February 2020. <nit.com.au/andrea-mason-oam-to-write-unwritten-chapter-of-first-nations-disability-in-royal-commission>

49 *Letters Patent* (Cth), 4 April 2019 amended 13 September 2019, (g).

50 Australian Bureau of Statistics, *Disability, Ageing and Carers, Australia: Summary of Findings, 2018,* Catalogue number 4430, 24 October 2019. Results accessed using Australian Bureau of Statistics TableBuilder Disability status by Whether has a disability and Main language spoken at home.

51 Federation of Ethnic Communities' Councils of Australia, *New and emerging communities in Australia: Enhancing capacity for advocacy*, Report, 2019, p 3.

52 Transcript, the Chair, Public hearing 1, 16 September 2019, P-15 [1–3].

53 Name withheld, Submission, 20 February 2020.

Part A: About the Royal Commission

Part A of the interim report describes the background to the Royal Commission and its nature and scope.

Chapter 1, ‘Why this Royal Commission is needed’ gives a brief history of the discrimination, disadvantage and maltreatment experienced by people with disability and describes the events leading up to the establishment of the Royal Commission. The chapter concludes with one person’s experience, which illustrates the importance of our task.

Chapter 2, ‘Our Chair and Commissioners’ introduces the Chair of the Royal Commission, the Hon Ronald Sackville AO QC, and Commissioners.

Chapter 3, ‘Our terms of reference’ describes the scope of the inquiry, as set out in the terms of reference. It discusses how the Royal Commission’s work is informed by human rights. It also highlights what makes this inquiry distinctive.

Chapter 4, ‘Nature and powers of the Royal Commission’ looks at how the Royal Commission collects, compels, protects and shares information. It explains key provisions of the *Royal Commissions Act 1902* (Cth), the powers of the Royal Commission and how the Act regulates the conduct of this inquiry.

Chapter 5, ‘Our organisation’ provides an overview of our organisation and the values that guide our work. It describes our Accessibility and Inclusion Strategy, which guides how we recruit and train staff and select and set up venues for our public hearings and engagement activities.

Content warnings

Please be aware that this report contains information that may be distressing to readers.

It includes accounts of violence against, and abuse, neglect and exploitation of, people with disability and references to suicide and self-harming behaviours.

In some first-hand accounts of violence, abuse, neglect and exploitation, people have told us of abusive or offensive language they have experienced or witnessed. As a result, some direct quotes in the report contain language that may be offensive to some people.

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

If you need support to deal with difficult feelings after reading this report, there are free services available to help you. Information about these services can be found at the beginning of this report (see page vi) and in Chapter 6, ‘Support for people engaging with the Royal Commission’.

1. Why this Royal Commission is needed

Key points

- Throughout Australia's postcolonial history, people with disability have experienced discrimination, segregation and violence.
- People with disability represent 18 per cent of the Australian population. They are more than twice as likely as people without disability to have experienced violence in the last 12 months.
- Thirty-eight per cent of First Nations people have disability. Six per cent of First Nations adults with disability experienced physical violence in the past 12 months.
- The trauma arising from violence, abuse, neglect and exploitation can have long term physical and psychological effects.
- The disability rights movement has led the way in pushing for social change to improve the lives of people with disability.
- People with disability have been strong and determined advocates for themselves and others.
- Revelations of sexual abuse in Victoria and a federal Senate inquiry into violence, abuse and neglect against people with disability in institutional and residential settings were two of the key factors that led to the establishment of this Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability.

Introduction

Disability advocates and their supporters argued strongly and persistently over many years for a royal commission into violence against, and abuse, neglect and exploitation of, people with disability. The result of their efforts was the issue of the Commonwealth Letters Patent on 4 April 2019 establishing this Royal Commission.[1]

The Royal Commission's terms of reference direct us to inquire into:

> [w]hat governments, institutions and the community should do to prevent, and better protect, people with disability from experiencing violence, abuse, neglect and exploitation, having regard to the extent of violence, abuse, neglect and exploitation experienced by people with disability in all settings and contexts.[2]

People with disability are a diverse group, and the experience of individuals varies. People with physical, sensory and cognitive impairments may experience different forms of disadvantage.[3] The experience of discrimination may also be affected by age, sex, gender, gender identity, sexual or gender orientation, intersex status, ethnic origin or race.[4] First Nations and culturally and linguistically diverse people with disability can experience multi-layered discrimination and disadvantage.[5]

There is, however, a shared experience of disadvantage and exclusion that arises because society is not yet structured to fully include people with disability.[6]

Overall, people with disability experience certain kinds of disadvantage much more frequently than other members of the Australian community. These include:[7]

- lack of access to buildings, facilities and services
- reduced opportunities for employment
- increased levels of poverty
- discrimination in many sectors of life
- segregation and social exclusion.

Most importantly for this Royal Commission, people with disability also experience much higher levels of violence, abuse, neglect and exploitation than other members of the Australian community.[8]

Just as the forms of disadvantage experienced by people with disability vary, so do the nature and extent of violence, abuse, neglect and exploitation that individuals with disability experience. The seriousness of the problem is beyond dispute. It has been explicitly recognised in many official reports over many years.[9]

Australian governments have not entirely ignored the problem. Largely as a result of advocacy by people in the disability rights movement, some important steps have been taken to address the maltreatment of people with disability.[10] Even so, as this interim report shows, the levels of violence, abuse and other forms of maltreatment experienced by people with disability continue to be unacceptable and often shocking (see Chapter 15, 'Nature and extent of violence against, and abuse, neglect and exploitation of, people with disability').

It is – or should be – self-evident that the impact of violence, abuse, neglect and exploitation can be and often is devastating to the lives of people with disability. Trauma, physical injuries, psychological damage and financial exploitation have profound consequences.[11] The denial of opportunities for education, employment and social inclusion prevents people with disability from fulfilling their potential. As we heard in Public hearing 4: Health care and services for people with cognitive disability, people with intellectual disability and those on the autism spectrum experience a range of multiple health conditions which are either not known or poorly managed. The result is poor health and, in some cases, potentially avoidable deaths.[12]

This chapter provides a brief overview of the history of discrimination, disadvantage and maltreatment of people with disability and traces some of the policy and social changes achieved through the efforts of the disability rights movement. It also outlines the events leading to the establishment of the Royal Commission and the consultations that determined our terms of reference. The chapter concludes with one person's experience, which illustrates the importance of the Royal Commission's task.

A brief history of violence against, and abuse, neglect and exploitation of, people with disability

For much of history in the Western world, people with disability have lived on the margins of society, subjected to discrimination, segregation, exclusion and violence.[13] While there are indications that First Nations peoples had more inclusive practices,[14] many 19th and early 20th century leaders in Australia joined others globally in attempting to remove 'defective' humans from society (that is, the practice of eugenics).[15] This occurred largely by segregating people with disability from the wider population and sometimes by sterilising girls with disability.[16] Although the experiences of people with disability should not be conflated with the horrific impact of colonisation on First Nations peoples, there are notable parallels, as both groups were considered inferior and were targets of dehumanising discrimination and segregation.[17]

During the 19th and much of the 20th centuries in Australia, many children born with disability were taken from their parents and locked away for life in large residential institutions.[18] Adults with disability were sometimes reduced to begging to stay alive.[19] Adults considered 'lunatics' (a category that included people with mental health conditions and intellectual disability) were sent to asylums.[20] While the philosophy behind the creation of these institutions was that they would protect people from a life of poverty and exploitation on the streets, in reality they were oppressive and people with intellectual, physical and psychosocial disability had little or no control over their own lives.[21] They typically suffered poor medical and health treatment and poor diets, and received minimal education.[22] They were subjected to violence and sexual assault, and had no way to report the abuse and seek redress through the justice system.[23]

Women and girls with disability were sometimes sterilised without consent.[24]

Through to the 1960s and in some cases beyond, people with disability living in the community were also kept out of sight, unable to access many public spaces.[25] Those who were visible were pitied and often mocked, and sometimes paraded in circuses and ‘freak shows’.[26]

Lena*

When Lena arrived for her first shift as a disability support worker in a day centre, she expected it to be as advertised.

'On paper the roster of programs looked fantastic,' she told us. Participants, some with high needs, could choose different activities – for example, cooking, sewing, woodwork and drama. 'They should have been enjoying their life, but they weren't.'

Instead she was confronted with 32 people, some restrained, some wearing face guard masks and some lying on the floor. There were only two staff and Lena was told to 'get on with it the best you can'.

The restraints were 'the old fashioned chairs with belts on them … and people that were ambulant … would be strapped in'. The masks were forced on people to stop them spitting. Lena was shocked because 'the newer restraint laws would definitely have been in'.

One man was lying on the floor eating chips. Lena was worried he might choke and tried to sit him up but was told, 'just leave him alone, there is nothing you can do'.

The participants also had set bathroom times. One man had already used his bowels and Lena told her supervisor he needed to go to the toilet. The supervisor replied 'we can't take him now, it's not his time'.

Lena's second shift wasn't much better and she put this down to the culture. The staff were old, institutionally trained or untrained; 'you don't even need a certificate anymore for casual staff'. Two shifts were enough. 'It was revolting,' she said.

The next place she worked was run by the same company and she did one-on-one support. All the residents had complex behaviours including physical violence, compulsive eating and absconding. All doors, windows and the kitchen roller door were locked.

The man Lena supported was a compulsive eater. Food soothed him, and he knew the staff kept their chocolates in the office. One day the supervisor found him there and yelled 'what the fuck are you doing' and told him to get out. When the man hesitated, the supervisor grabbed him and physically removed him. Lena reported the supervisor to her manager but was told it wasn't her place to say anything. 'I was casual and I didn't want to lose my job.'

She supported the same man at a community centre during the day where the kitchen was open and lunch boxes were left out. With Lena's help he learned not to touch food that didn't belong to him.

Lena also recounted supporting a woman living in a residential facility for 30 men and women. Half the residents had a disability and half had been recently released from prison. Doors weren't locked. For people with no support it was a place of last resort, 'before homelessness'.

The home kept 85 per cent of the residents' support pension for food, toiletries, and health expenses. Residents were supposed to be given the remaining 15 per cent but this woman was lucky to get $10 a week. Food was served at strict times and toiletries were restricted. Lena says, 'I had to go every week and ask for soap … tampons … shampoo'. Laundry was done only twice a week, so clean clothes were an issue. Rooms weren't cleaned. The residents' cigarettes were taken and kept in reception which was only open during the day.

The woman Lena supported had an acquired brain injury and was terrified of the dark. There was an issue with the electricity in her room and 'there was never a proper electrician called in to fix [it]'. She had no lights and no television. She was terrified, alone and unable to lock her door. A colleague told Lena multiple rapes had been reported.

When Lena left the woman ran away. The police found her and brought her back. Lena returned and did a few shifts with her and the woman talked about feeling suicidal. Lena immediately told her supervisor who said Lena was 'just a support worker and it wasn't my business and it wasn't their job to look after her'.

Lena says she tried to put clients in touch with disability advocates but found herself in a 'feedback session' and was told if she ever gave a disability advocate's number to a client again, 'I would lose my job … they don't need advocacy'. She tried to report her employer but couldn't find an appropriate avenue.

Lena now also works as a disability advocate and is determined to support people who have no-one to speak up for them.

*** Name changed and some details removed to protect people's identities. Narrative based on a private session with the Royal Commission.**

Achievements of the disability rights movement

The disability rights movement formed globally in the 1970s and 1980s.[27] Led by people with disability, the movement campaigned to change the attitudes and practices that contributed to discrimination and disadvantage. People with disability and other advocates fought to close residential institutions.[28]

In Australia, the first documented direct action occurred in 1971. John Roarty, a 50-year-old man with cerebral palsy who had lived in Weemala Nursing Home in Sydney, New South Wales, since he was 16 years old, formed a residents committee to protest their maltreatment.[29] Weemala, previously named the Home for Incurables, 'was run like a prison with strict rules for behaviour management, outings, fraternisation with fellow residents and staff'.[30] The committee's list of demands was ignored at first by Weemala management, which threatened to throw the campaigners out if they did not desist. Undeterred, the committee took its concerns to the media, and management subsequently relented.[31]

In the decades that followed, the disability rights movement in Australia led powerful protests against the exclusion of people with disability from public spaces, blockading inaccessible public transport and squatting in parliamentary offices.[32] The movement was empowered by what has become known as the social model of disability. The social model changes the focus from the functional limitations of individuals with impairments to the problems caused by disabling environments, barriers, attitudes and cultures (see Chapter 16, 'Our theoretical approaches').[33]

The social model has been the subject of much discussion during the past three decades. It has been used by disability advocates in Australia and globally to press for legal and policy reforms and to agitate for increased public awareness of disability issues.[34] The changes brought about by this advocacy have included improved access to transport, public buildings and communications, and, for children, to mainstream schooling.[35]

The campaigns led to a series of law reforms, including the development of anti-discrimination laws in all Australian states and territories,[36] and the introduction of the *Disability Discrimination Act 1992* (Cth) (*DDA*).[37] The objects of the *DDA* seek to eliminate discrimination against people on the grounds of disability and 'ensure, as far as practicable, that persons with disabilities have the same rights to equality before the law as the rest of the community'.[38] The introduction of anti-discrimination legislation provides people with disability a framework for protecting their rights, including through the making of complaints about unlawful discrimination.[39]

In 2008, Australia ratified the *Convention on the Rights of Persons with Disabilities* (*CRPD*).[40] The *CRPD* is the culmination of decades of work by the disability rights movement globally, including significant contributions by the Australian disability community.[41] It has been hailed as a ‘landmark in the struggle to reframe the needs and concerns of persons with disability in terms of human rights’.[42] The purpose of the *CRPD* is to promote, protect and ensure the full and equal enjoyment of the human rights of all people with disability,[43] and imposes obligations on States Parties (that is, countries who have accepted obligations and duties under the *CRPD* at international law) to protect, ensure and promote these rights.[44]

The *CRPD* has helped to advance the rights of people with disability around the world, including in Australia.[45] The human rights of people with disability and the *CRPD* are explicitly referenced in our terms of reference,[46] specifically Article 16 of the *CRPD*, which requires States Parties to ‘take all appropriate measures to prevent all forms of exploitation, violence and abuse’ against people with disability.[47]

The introduction in Australia of the National Disability Insurance Scheme (NDIS) (refer to Appendix D for an overview of the NDIS) in 2013 is another example of the achievements of the disability rights movement, together with governments and the wider public.[48]

Discrimination and disadvantage continue

Despite these important advances, people with disability in Australia still experience discrimination and disadvantage. The process of closing large residential institutions is not yet complete.[49] In 2018, there were around 5,300 people aged under 65 living in the cared component of a residential aged care facility[50] (a situation that the Royal Commission into Aged Care Quality and Safety has recommended be corrected, which the Australian Government has committed to doing).[51] For people moved out of institutions into group homes and other settings, their situation did not always improve.[52] As stated in the 2009 *Shut out* report to the Australian Government by the National People with Disabilities and Carer Council:

> Many people with intellectual disability live in group homes, and while some would argue that this is an improvement on the previous large institutional arrangements, these environments still congregate and segregate people in a way which inhibits community inclusion. Further, people living in these arrangements have very little choice about who they live with, whereas non-disabled community members who choose to share accommodation with others generally do have this choice.[53]

The *Shut out* report identified problems in the provision of support services and in part led to the establishment of the NDIS.[54] It also highlighted abuse of children with disability, violence against people with intellectual disability in group homes, and sexual assault of women and men with disability.[55] It reported on human rights violations and the neglect of basic survival related needs.[56] It highlighted the multi-layered disadvantage of culturally and linguistically diverse people with disability and First Nations people with disability, whose experiences of discrimination are often compounded by racism.[57] The report gave voice to the assertion of people with disability that they still face violence, abuse, neglect and exploitation. It also paid tribute to the resolve of the disability community to bring about change, stating: ‘People with disabilities are determined and strong. They fought hard to achieve their goals. They refused to take no for an answer.’[58]

The campaign to establish the NDIS further united and encouraged the disability rights movement. After that success, the movement focused its attention on other issues that had long been of concern. Advocates fought against the exploitation of people working in Australian Disability Enterprises (previously known as ‘sheltered workshops’) who receive far less than the minimum wage.[59] They spoke out about abuses of people with disability in the criminal justice system, including indefinite detention and violence against First Nations people with disability.[60] They raised concerns about people with cognitive and psychosocial disability being held against their will in psychiatric centres.[61] They pressed for an end to the use of physical and chemical restraints to control the ‘behaviour’ of people with disability.[62] They have raised concerns about Australian laws that have allowed for the sterilisation of women and girls with disability.[63]

In her statement to the Royal Commission, Sally Robinson, Professor in Disability and Community Inclusion at Flinders University, summarised ongoing issues:

> People with disability are subject to stigmatising and discriminatory social, cultural, and structural ‘rules’ about their place in society. These are about being damaged, ‘other’, less than human, and needing to be in ‘their place’. This leads to oppression, isolation, and dehumanising of people with disability – all conditions which substantially increase the likelihood of abuse occurring and recurring.[64]

Disability support in Australia has improved since the 1970s. However in submissions to the Royal Commission, people with disability said they are still concerned about the fear, ignorance and prejudice that is common in our society.[65] Mr Cameron Algie AM, who has been vision-impaired for over 50 years, told us:

> There is a fear of blindness deeply seated in our human psyche, that loss of sight means lack of capability, even an end to a life worth living.[66]

Several witnesses at Public hearing 4 described how negative attitudes or assumptions affected them or their children from the moment disability was observed, and also when their children were seriously ill.[67] Dr Rebecca Kelly is the mother of eight-year-old Ryan Kelly, whom she describes as a ‘wonderful, kind, happy and very cheeky human being’.[68] She told us:

> Women are often given the diagnoses in negative terms, so first of all talking about a ‘risk’. We don’t talk about the risks of winning Lotto, we talk about the risk of people dying of cancer.

> Risk is inherently associated with bad outcomes. Risk sends a message that Down syndrome itself – and intellectual disability more generally – is a negative thing and it reinforces these outdated concepts around disability.[69]

In submissions we have been told there are common assumptions that disability is a tragedy and people with a disability would be better off dead or not having lived.[70] Disability advocates and researchers say that such assumptions contribute to the violence, abuse, neglect and exploitation that is still the common experience of Australians with disability.[71]

Disability in Australia

The need for the Royal Commission arises not only from the history of discrimination and disadvantage in Australia, but from the large number of people with disability in the population. Any one of us could incur an injury-related impairment, especially as we age. (As noted in Chapter 3, 'Our terms of reference', there is some overlap between our terms of reference and those of the Royal Commission into Aged Care Quality and Safety, and arrangements are in place to facilitate cooperation and clarify responsibilities between the two inquiries.)

The nature of disability and the number of people with disability

In 2018, there were around 4.4 million people with a disability in Australia, representing 18 per cent of the population.[72] The distribution of people with disability by age group in 2018 is represented in Table 1.1.[73]

Table 1.1: Number and percentage of people with disability by age group, 2018

Age group	Number of people with disability ('000')	Percentage of age group with disability
Children, aged under 18	453.7	8.2%
Adults aged 18–64	1969.7	12.9%
Adults aged 65+	1941.5	49.6%
Total	**4367.2**	**17.7%**

Note: The numbers for each age group of people with disability do not add up to 4367.2 because the Australian Bureau of Statistics changes some numbers to protect the confidentiality of people completing the survey.

Source: Australian Bureau of Statistics (2019).

Around 1.4 million people (or nearly 6 per cent of the population) experience what the Australian Bureau of Statistics defines as a 'profound or severe' disability.[74] According to the Bureau, profound or severe disability means a person is unable to do, or always needs help with, tasks related to self-care, mobility or communication; or that they sometimes need help with self-care or mobility but have difficulty understanding or communicating with others.[75] People with intellectual disability, psychosocial disability and those who have experienced a head injury, stroke or acquired brain injury tend to experience higher rates of profound or severe disability than people with other disability types.[76]

The percentage of First Nations people with disability is substantially higher than the percentage of people with disability in the non-Indigenous population. In 2018–19, around 306,100 First Nations people had disability, representing 38 per cent of the First Nations population.[77] There were around 66,100 First Nations people with a profound or severe disability, representing around 8 per cent of First Nations people.[78] The distribution of First Nations people with disability by age group is shown in Table 1.2.[79]

Table 1.2: Number and percentage of First Nations people with disability by age group, 2018–19

Age group	Number of First Nations people with disability ('000')	Percentage of First Nations population
Children, aged under 18	73.0	22.3%
Adults aged 18+	233.6	48.1%
Total	**306.1**	**37.6%**

Note: The numbers for each age group of First Nations people with disability do not add up to 306.1 because the Australian Bureau of Statistics changes some numbers to protect the confidentiality of people completing the survey.

Source: Australian Bureau of Statistics (2019).

The nature and extent of violence, abuse, neglect and exploitation against people with disability

While many people have spoken out about violence against, and abuse, neglect and exploitation of, people with disability, there is not a lot of publicly available data on its extent in Australia.

The best available data from the Australian Bureau of Statistics suggests that in 2016, almost 2.4 million people with disability aged 18–64 years (almost two in three) had experienced physical or sexual violence, emotional abuse, stalking or harassment in their lifetime.[80] People with disability were twice as likely as people without disability to have experienced violence in the previous 12 months.[81]

Sexual violence towards people with disability is gendered, as it is for people without disability. While all women are at higher risk of sexual violence than men, women aged 18–64 years with disability are twice as likely to have experienced sexual violence in the past 12 months as women without disability.[82] Young people are also at higher risk than other age groups. In a 12-month period, one in four people aged 18 to 29 years with disability (around 166,000 people) are estimated to experience violence, compared with around one in 10 people with disability aged 45 to 64 years.[83]

First Nations people with disability experience high rates of violence. In 2018–19, around 15,100 First Nations adults with disability (6 per cent) had experienced physical violence in the past 12 months.[84] In Chapter 18, 'First Nations people with disability' we provide more detail on the multi-faceted discrimination and disadvantage that come from ethnicity or race as well as disability. First Nations people with disability are at substantial risk of harm, including poor physical and psychological health outcomes, low educational attainment, low levels of employment and a high likelihood of having been removed from their family and detained against their will.[85]

In Chapter 15, we provide further data on the nature and extent of violence against, and abuse, neglect and exploitation of, people with disability in Australia.

In addition to the ordeal of specific events, violence, abuse, neglect and exploitation have negative long term impacts on the health and wellbeing of victims of abuse as well as their families, communities and society as a whole.[86] At Public hearing 3: The experience of living in a group home for people with disability, we heard evidence that:

> A series of individual incidents of emotional abuse or neglect, together with inappropriate and inadequate system responses over time, may comprise psychological abuse or neglect and cause lasting damage to the person.[87]

Further, in Public hearing 4, we heard that over a 6.5 year period in New South Wales, 38 per cent of all deaths of people with intellectual disability were potentially avoidable.[88] This rate is more than twice that of people without disability.[89]

Jane and Maree*

> **Ten years on from the initial sexual abuse, our daughter … still suffers from PTSD [post-traumatic stress disorder], distrust issues, life threatening psychogenic seizures, anxiety and depression requiring medication and many fears.**

Jane, Maree's daughter, is autistic. She began having seizures as a baby, resulting in development delays and challenging behaviours. Maree told us in her submission that Jane's autism wasn't properly diagnosed until her early teens.

By the time Jane was in her late teens, Maree was 'worn out' because of lack of support. So she and her husband made the decision for Jane to live in a care home supported by a large agency. She describes it as a 'traumatic option' but the only one possible at the time.

Maree told us that Jane was excited at the idea of living independently. But although Jane was very happy with the night and weekend staff, she had many issues with the day staff. Her behaviour management plan was never followed and instead she was subjected to humiliation, intimidation and bullying. Maree complained to the day service staff and eventually to the general manager. Her emails went unanswered and she felt that staff avoided her.

In her submission Maree describes ringing one night to speak with Jane. The staff member who answered asked if the agency had been in touch regarding the 'critical incident'. Maree hadn't heard about it. Then Jane told her she had been sexually abused by a staff member. Maree told us that when she called the agency the next morning they asked, 'Oh you think that happened? Do you want us to get the police involved?' Maree was adamant that she did. Two weeks later Jane was interviewed by the police.

Maree told us that in the 20 months it took for the case to go to trial, Jane was in a constant state of anxiety and the agency offered her no support. Jane developed a fear of new people supporting her. When new support people were introduced, she was scared of them and told Maree they were hurting her. Jane's behavior escalated and police were called.

Maree recounts in her submission that the staff member was found guilty and sentenced to prison. The prosecutor was surprised because it is 'quite rare for a person with a disability to win a case of abuse', as they are not considered reliable witnesses. However, the conviction was overturned on appeal. Maree told us she felt that a factor in this outcome was that Jane had to engage with a series of prosecutors who lacked understanding of autistic people, while the defendant had one lawyer for the entire process.

Maree says that Jane was left angry, fearful, anxious and distrusting, and behaved accordingly. She says the service provider suggested Jane would benefit from a stay in their lockdown facility to 'help people with challenging behaviours'. Maree wanted to see the facility and a behaviour management plan, but says this never happened. Instead, she says, they placed Jane there one weekend when they were short-staffed and suggested Jane have no contact with Maree or her favourite people.

Maree states that when, after 10 days, she was allowed to see Jane, she was appalled at the conditions – there was nothing to do and Jane had been denied her personal possessions. Maree believes 'this place, and how she was treated, has become a trigger to the fears and nightmares' Jane still experiences.

Maree and her husband brought Jane home. Maree told us Jane was severely damaged by the experience and blamed Maree for sending her there. She said Jane was fearful of home support staff and reacted aggressively.

Maree's submission describes Jane having post-traumatic anxiety attacks. During these attacks, which are like seizures and can last for hours, she requires incontinence pads, rails on the bed, a helmet and a wheelchair. 'This is a young woman who is normally very physically able and is continent,' says Maree.

Jane is living out of home again and things seem better, but what happened to her 'continues to have an impact on her daily life … on our family and her carers'.

Maree told us she would like to see more comprehensive training for people working in the disability system and the legal system so they understand autism and associated behaviours.

*** Names changed and some details removed to protect people's identities. Narrative based on a submission to the Royal Commission.**

Events leading to the establishment of the Royal Commission

Ratification of the *CRPD*

The 2008 ratification of the *CRPD* by Australia and most nation states was a turning point for disability rights worldwide.[90] It set in motion processes that held nations to account for their record of realising the human rights of people with disability.[91]

The *CRPD* recognises the rights of people with disability in many areas. Article 16 of the convention is about freedom from exploitation, violence and abuse. It requires Member States to:

> take all appropriate legislative, administrative, social, educational and other measures to protect persons with disabilities, both within and outside the home, from all forms of exploitation, violence and abuse, including their gender-based aspects.[92]

Australia's national response to the ratification of the *CRPD*

In response to the *CRPD* and the findings of the *Shut out* report, the Council of Australian Governments (the peak inter-governmental forum in Australia) developed the National Disability Strategy 2010–2020.[93] The strategy sets out national commitments and plans to improve the lives of Australians with disability, their families and support people. It includes a commitment to rights protection, justice and legislation that ensures people with disability are 'safe from violence, exploitation and neglect'.[94] It undertakes to ensure that people with disability will receive 'more effective responses from the criminal justice system'.[95] It sets out plans for economic security, personal and community support, education and the health and wellbeing of all Australians with disability. The strategy seeks to focus on improving the outcomes for First Nations people with disability.[96]

Ratifying the *CRPD* and publishing the National Disability Strategy showed that the Australian and state and territory governments were open to hearing the voices of people with disability.[97] This openness became apparent with the success of the drive for the NDIS. In 2011, the National Disability and Carer Alliance launched a campaign for the implementation of the NDIS.[98] The campaign, Every Australian Counts, became a grassroots movement that lobbied all members of the Australian Parliament and achieved widespread media coverage.[99] It showed people with disability not as victims but as active campaigners for change.[100] The agreement of all major political parties to enact the NDIS was an important reminder of the power of the collective voices of people with disability.[101] It encouraged united action to address issues not covered by the NDIS, especially injustice and violence.

Public respond to ongoing abuse and violence

In late 2012, the Victorian Advocacy League for Individuals with Disability (VALID) and other disability advocates began calling for a royal commission into institutional abuse against people with disability.[102] Two years later, on 24 November 2014, a joint media investigation by the Australian Broadcasting Corporation (ABC) and Fairfax Media aired on *Four Corners*, the ABC's leading investigative journalism program.[103] The 'In our care' report detailed numerous instances of sexual assault, harassment and inappropriate behaviour at homes run by Yooralla, one of Australia's largest disability service providers. Among these was the case of Vinod Kumar, a disability support worker employed by Yooralla on a casual basis.[104] Mr Kumar had been charged by Victoria Police in March 2012 with multiple counts of rape and other sexual offences against people with disability in his care at supported accommodation provided by Yooralla.[105]

Two days after the *Four Corners* report aired, Australian Greens Senator Rachel Siewert moved a motion in the Australian Senate calling on the Australian Government to hold a national inquiry into abuse against people with disability.[106] She told the Senate:

> [i]f we think that this abuse is only limited to Victoria, we are very sadly mistaken … We have [a] … national obligation to investigate this and put in place measures to ensure that people with disability are safe and protected and are not subjected to violence or abuse.[107]

In early 2015, a group of disabled persons' organisations, including Women with Disabilities Australia, People with Disability Australia, National Ethnic Disability Alliance, First Peoples Disability Network Australia, and United Voices for People with Disabilities Inc, wrote to then Prime Minister, the Hon Tony Abbott, about the violence and abuse committed against people with disability. They requested that he 'urgently establish an independent National Inquiry'.[108]

Community Affairs References Committee Inquiry

That same year, the Australian Senate directed the Community Affairs References Committee to inquire into and report on 'violence, abuse and neglect against people with disability in institutional and residential settings'. The committee received 160 submissions and held six public hearings.[109] Among those to appear before it were disability advocates the Bolshy Divas, who read out a list of harrowing abuses against people with disability.[110] Other submitters expressed concern that lack of accommodation options meant that people who were not compatible were forced to live together.[111] VALID stated that people are required 'to live in group accommodation with other residents who make their lives unsafe, miserable and intolerable'.[112]

The committee's November 2015 report concluded that 'violence, abuse and neglect of people with disability is both widespread and takes many forms'.[113] It identified the root cause of violence as the devaluing of people with disability: 'This devaluing permeates the attitudes of individual disability workers, service delivery organisations and most disturbingly, government systems designed to protect the rights of individuals.'[114] The committee concluded that it was 'convinced that violence, abuse and neglect against people with disability is widespread' based on the substantial witness testimony it received.[115] It also noted 'with great concern, the lack of reliable and consistent data on violence, abuse and neglect of people with disability, and the complete lack of data on the outcomes of reporting and investigations'.[116] It made 30 recommendations, including the establishment of a royal commission to investigate violence, abuse and neglect of people with disability.[117]

Victorian Parliamentary Inquiry

Also in 2015, the Victorian Parliament held an Inquiry into Abuse in Disability Services.[118] Its 2016 report stated that the Inquiry had heard 'undeniable evidence of the widespread nature of abuse and neglect of people with disability over a long period of time'.[119] The report said the Inquiry received information about 'criminal physical and sexual assault, verbal and emotional abuse, financial abuse, and neglect endangering life'.[120] Among its many recommendations was that the Victorian Government support a federal royal commission into violence against people with disability. The report said:

> A federal Royal Commission would send a powerful message to the broader community about the seriousness of the abuse of people with disability, and would serve as an opportunity for governments across Australia to work cooperatively on developing strategies for prevention.[121]

Public calls for a Royal Commission

Between 2016 and 2018, disability advocates around the country continued to call for a royal commission. On 5 April 2017 more than 100 academics signed an open letter to the then Prime Minister, the Hon Malcolm Turnbull. They described significant research showing that 'people with disability experience higher rates of violence, abuse and neglect than the rest of the community, and that women and children with disability are disproportionately impacted by this violence'.[122]

In May 2017, then Opposition Leader, the Hon Bill Shorten MP, pledged to establish a 'royal commission into abuse of people with disabilities' if the Australian Labor Party won the next federal election, saying:

> A royal commission is needed so that people with disability, their families and carers can tell their stories to the highest level of judicial inquiry and seek justice. This will be a vital part of a national healing process.[123]

Adding to the momentum for a royal commission, in June 2018, under the direction of then Disability Discrimination Commissioner Mr Alastair McEwin AM, the Australian Human Rights Commission published *A future without violence*.[124] It analysed violence against people with disability in institutional settings and made several recommendations.

The report noted:

> Inquiries that have been undertaken into this issue have called for independent, external oversight of institutional settings, more robust reporting and complaints mechanisms, and increased regulation of disability service workers. This report has reached similar conclusions.[125]

In November 2017, Western Australian disability advocate Jordon Steele-John was elected as an Australian Greens Senator.[126] A person with disability and a wheelchair user, his inability to access the floor of the Senate chamber highlighted the inaccessibility of key areas of Parliament House.[127] While there have been parliamentarians before Senator Steele-John with disability, he took up the role as a passionate advocate for people with disability.[128] He is generally credited as the man 'who urged' his fellow parliamentarians into establishing the Royal Commission.[129]

On 14 February 2019, the Senate voted in favour of a motion moved by Senator Steele-John calling on the Australian Government to establish a royal commission into violence, abuse and neglect of people with disability.[130]

Announcement of the Royal Commission

Four days later, on 18 February 2019, the Government supported the motion when it reached the House of Representatives.[131] The Prime Minister, the Hon Scott Morrison MP, told Parliament he would seek further advice from all states and territories on establishing the Royal Commission, and would consult 'directly and extensively' with stakeholders on the terms of reference.[132] He also pledged $527.9 million to fund the inquiry.[133]

The Australian Government Department of Social Services conducted a public consultation on the draft terms of reference. It consulted with people with disability, their families and support people, disability peak bodies, advocates and state and territory governments.[134] The department received 65 written submissions, and 3877 people completed a public survey.[135] It also consulted with and received the support of all state and territory governments.[136]

The consultation showed overwhelming support for the Royal Commission to cover all settings and contexts in which violence, abuse, neglect and exploitation occur.[137] These settings include 'in disability services, health and hospital settings, shared living arrangements, educational settings, workplaces and government organisations'.[138] As the Bolshy Divas observed:

> Disability abuse is complex, multidimensional and is experienced in a range of settings, including service settings and the family home … We believe that narrowly defining the scope of this inquiry will hinder an adequate investigation.[139]

The consultation emphasised the importance of ensuring that the experiences and stories of people with disability are central to the Royal Commission.[140] There was strong affirmation that people with disability should be at the centre of the work of the Royal Commission and future decision making.[141] As stated by Disabled People's Organisations Australia:

> In keeping with Australia's obligations under the *CRPD*, the Royal Commission must be driven by the experiences of those of us who have experienced violence, abuse, exploitation and neglect. This should be the first task of the Commission – to hear from us about our experiences. Doing so will enable the Commission to undertake all other aspects of the Commission through this lens.[142]

Several submissions called for particular attention on First Nations people with disability, who experience multiple layers of discrimination.[143] Others suggested that the language in the terms of reference should more closely align with the *CRPD*.[144] Some did not like the references in the *CRPD* to people with disability needing protection, which they viewed as paternalistic, and preferred to emphasise more empowering language such as agency and inclusion.[145] These different perspectives highlight the diverse views within the disability community.

Submissions also identified the need to provide appropriate, independent advocacy support to people with disability who wanted to engage with the Royal Commission.[146] This included providing culturally appropriate supports, legal assistance and specific supports for people with cognitive and psychosocial disabilities.[147] On the importance of hearing the voices of people with disability, Disabled People's Organisations Australia stated:

> It is critical that the Royal Commission is centred on and grounded in the voices of those of us who have experienced violence, abuse, exploitation and neglect, including those of us who have acquired our disability as a result of violence.[148]

Accessibility and inclusion were central themes of many submissions.[149] Women with Disabilities Victoria said:

> The Royal Commission must also be accessible: reasonable adjustments, support and information must be made available and information provided in a range of community languages and accessible formats. People with disability must be provided with support services and community groups that have an understanding of particular intersectional disadvantages.[150]

Some submissions emphasised the need to mirror the provision of redress in the terms of reference of the Royal Commission into Institutional Responses to Child Sexual Abuse.[151] Some said that the Royal Commission should have powers to investigate and prosecute.[152] In addition, some submissions argued that the Royal Commission needed a solid information base about people with disability and their experiences. They called for improved data and research on violence and abuse towards people with disability to address knowledge gaps.[153]

On 5 April 2019 Prime Minister Morrison announced the establishment of the Royal Commission, saying:

> Violence, abuse, neglect and exploitation of people with disability is unacceptable and abhorrent and it's critically important to make this truly a national inquiry.[154]

Full details on the terms of reference are set out in Chapter 3.

Past inquiries and reports

The Royal Commission was established in the context of repeated calls from people with disability, their advocates and representative organisations about the need to address violence against, and abuse, neglect and exploitation of, people with disability.[155] We also know that there have been a large number of inquiries and reports conducted by various levels of government that relate to our terms of reference.

In Chapter 11, 'Research and policy', we outline how we are examining the findings and recommendations of previous relevant reports and inquiries. This includes a large research project to identify relevant past reports and inquiries and to analyse their findings and recommendations. To date we have identified more than 240 relevant past reports and inquiries. We will analyse each report as well as information collected through our compulsory powers (see Chapter 4, 'Nature and powers of the Royal Commission', for more detail on our compulsory powers). We will also examine information we receive via submissions, our research and public hearings, and publicly available material on the implementation of previous recommendations.

This research project provides insight into how previous inquiries and reports have sought to address violence against, and abuse, neglect and exploitation of, people with disability. It will enable us to determine which recommendations from previous inquiries we might endorse as being applicable. It will highlight factors that facilitate or act as barriers to the implementation of recommendations. This will help us frame our recommendations in our final report.

The impact of violence, abuse, neglect and exploitation

This chapter describes the long history of discrimination, disadvantage and violence against people with disability in Australia. It also highlights the strength of the disability community in resisting that violence and advocating for change. It sets out data showing that people with disability experience violence and abuse at much higher levels than people without disability. It describes the events that led to the announcement of the Royal Commission and the consultations that established the terms of reference.

Yet for all of this information, it is hard for people with little experience of disability to understand the significant impact of violence, abuse, neglect and exploitation on the whole of a person's life. It is the experiences of people with disability and their families that best show why the Royal Commission is needed.

At our Public hearing 3, we heard from Ms Jane Rosengrave.[156] The experience she described is one of segregation, violence and abuse, but it is also one of strength, hope and freedom. It is representative of the many experiences that sit behind the data and advocacy described in this chapter.

Ms Rosengrave is a person with an intellectual disability who is committed to self-advocacy.[157] She has served four years on the board of First Peoples Disability Network Australia.[158] She also works with several advocacy organisations.[159] She says of herself:

> I am an Indigenous woman which I'm so proud of, and my tribe is Yorta Yorta from Shepparton, and that, and I do painting, crocheting, watching the footy, cricket.[160]

In 1968, when she was five years old, Ms Rosengrave moved to the Pleasant Creek Training Centre in Stawell, Victoria.[161] A former hospital, it housed up to 140 children and adults with intellectual disability before it closed in 1999.[162] At the age of 16, Ms Rosengrave moved to a hostel on the grounds of Pleasant Creek with about 16 other residents where she said she was trained in how to live in a community residential unit (CRU).[163] One year later, Ms Rosengrave moved to a community residential unit operated by Pleasant Creek Training Centre (which today would be called a group home).[164] It was a large house that accommodated about seven residents, female and male.[165] Ms Rosengrave told us that she was given no choice about where she would live, and had little input into how she would spend her days.[166] Some of her time was employed at a 'work education centre', and she said she and other residents were not paid for their work.[167] Ms Rosengrave told us:

> I was feeling like our rights weren't there, our rights were taken away, and they were like little mini-institutions; they were … [E]ach morning the staff used to come up and say – knock on the doors and say, 'Everybody up ready for your breakfast and making the bed!'[168]

Asked whether she had a choice about whether she lived in the CRU or stayed in the institution, Ms Rosengrave said:

> We never had a choice at all. The staff were the ones with the thinking caps for us … Because they thought we were stupid, you know what I mean?[169]

When asked whether she felt heard while living in these environments, Ms Rosengrave said:

> No. We were just ignored. We were treated like a bunch of sheep from one paddock to another paddock. And I'm – I'm talking about the wards, girls' wards, from one paddock, senior girls' ward to another paddock, the hostel to another paddock.[170]

After having moved to the CRU, Ms Rosengrave told us that she was sometimes returned to the larger Pleasant Creek institution as punishment:

> I used to go back there sometimes for problems like epileptic fits or if I was dobbed in for not doing my job properly, and that, and the staff would make me stay down at senior girls for about two months. And that when there was no privacy because it was a very big ward. And there was some staff watching us getting undressed, having a shower, watch – you know, cleaning our teeth, you know, polishing the floors and all that.[171]

Ms Rosengrave said that residents in the home were separated from the wider community and often verbally abused:

> When I was living in the CRU [community residential unit] I felt – what's that word – socially isolated when we were abused in the street by people from the local community who used to call us nicknames, and that when we were in the streets – like – it's like when we used to go for our walks in the institution. And if there's people on the outside called us like mental case, spastic, retarded. And if we said that back to them we would get into trouble. It was like living in the CRU, the same thing that we would get into trouble for it.[172]

Ms Rosengrave told us that she was sexually abused by a bus driver who used to take her from the CRU to church. In her written statement she notes that she did not report the abuse at the time because, 'I felt, from my experiences living at institutions my whole life, that no one would believe me.'[173] In the hearing, she told us about its ongoing impact on her life:

> The man that continued to abuse me for three years, the abuse is still – it still affects me like today and it will for the rest of my life, it will, because when I'm talking about it I'm picturing it, I am.[174]

Ms Rosengrave has some good memories of her time at the home, including preparing meals for firefighters and attending occasional social events.[175] But she said it was not until she moved away from Pleasant Creek and was supported to live independently in the community that she felt free:

> I am a person with an intellectual disability. I currently live in a unit on my own in Melbourne which is run by Wintringham and I have been there for six years. The staff help me go to the doctors because they've been speaking jargon and all that. They even help me go to appointments and all that as well. Yes. And I – since I have lived in the city in the flat I am free as a bird, I am, and that's the way it's going to be for the rest of my life.[176]

The Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability exists for the sake of Ms Rosengrave and the many other people with disability whose experiences of violence, abuse, neglect and exploitation are, as Prime Minister Morrison noted, 'unacceptable and abhorrent'.[177] Her story needs to be heard, and we need to work out how to ensure that she and others with disability in our nation are included, safe and given every opportunity to flourish.

Endnotes

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Dev and Jana*

Jana's son Dev has Williams syndrome, is autistic and has a mild intellectual disability. She told us that in 2014 Dev was admitted to a children's hospital, where he was neglected by staff. She said, 'I am concerned that people with an intellectual disability or autism are not treated with equal regard or care in hospitals.'

In Jana's submission, she told us that Dev was seven years old when he had a rectal prolapse. The first time his parents took him to the children's hospital, the doctor on duty pushed the mucosa back in. Some days later, however, the mucosa prolapsed again and he returned to the hospital. Jana said the doctor pushed it back in again. He told her that, with children, prolapses usually resolve spontaneously. He said that surgeons only take action in serious cases and that the results were not great. He said there was very little they could do. 'It was obvious they were trying to discourage me taking this any further,' said Jana.

Jana explained that Williams syndrome means Dev's cells make less elastin, which helps tissue within the body maintain or resume its shape. So when she was told that the issue would resolve itself it made no sense at all to her. However, she decided to put her trust in the doctors and took Dev home to 'wait it out'.

Jana described the days and weeks that followed as a nightmare. The prolapse was out 24 hours a day and getting bigger. Dev was constantly straining, lying on the floor. He could not go to school, as he was incontinent and couldn't sit down. He couldn't go in the car and his parents couldn't leave the house. There were faeces all over the floor and they spent their days cleaning the house. Jana and Dev's dad took weeks off work to stay with him.

Jana contacted a private rectal surgeon to see if they could help, but they didn't respond. They finally returned to the children's hospital, where the doctor on duty said he would speak to a surgeon. It was clear to her that each doctor assumed her child was non-verbal. But, Jana said:

> My son knew exactly what was going on each time but was withdrawn due to distress. They did not always ask Dev's permission to physically examine his rectum and sometime did it while he was asleep. He would wake in extreme distress each time.

They finally met briefly with the rectal surgeon, who said he could definitely help. The doctor operated on Dev one and a half weeks later.

The surgery was a fantastic result, but Jana still wants to know why it took so long for the doctors to help Dev.

*** Names changed and some details removed to protect people's identities. Narrative based on a submission to the Royal Commission.**

2. Our Chair and Commissioners

Key points

- Seven Commissioners have been appointed to conduct the Royal Commission. The Hon Ronald Sackville AO QC is the Chair.
- The Commissioners have diverse backgrounds and expertise. This includes judicial and policy experience, disability leadership, First Nations leadership, and backgrounds in law reform, human rights, disability rights and support, and health.
- The Royal Commission has a range of mechanisms in place to ensure the Australian public can have confidence it will discharge its responsibilities independently and transparently.

Introduction

The Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability was established on 4 April 2019. On that date, the Governor-General of the Commonwealth of Australia issued letters patent under the *Royal Commissions Act 1902* (Cth).[1]

The letters patent are the official documents that create a royal commission, appoint the commissioners and, in the terms of reference, define the nature and scope of the inquiry. The terms of reference for this Royal Commission are very broad, and are discussed in detail in Chapter 3, 'Our terms of reference'.

The original letters patent appointed the Chair of the Royal Commission, the Hon Ronald Sackville AO QC, and five Commissioners:[2]

- Ms Barbara Bennett PSM
- Dr Rhonda Galbally AC
- Ms Andrea Mason OAM
- Mr Alastair McEwin AM
- the Hon John Ryan AM.

The Commonwealth letters patent were amended on 13 September 2019. Among other things, the amendments provided for the appointment of a seventh Commissioner, the Hon Roslyn Atkinson AO.[3]

Each state government has also issued letters patent establishing the Royal Commission under state legislation.[4] These letters patent are in substantially the same terms as those issued by the Commonwealth. This means that the Royal Commission has the authority to conduct its enquiries on a national basis, and investigate the actions and practices of state, territory and local governments and their agencies. The letters patent issued by the states have all been amended to correspond with the amendments to the Commonwealth letters patent.[5]

The Commonwealth letters patent are reproduced in Appendix A.

The Chair and Commissioners

Chair, the Hon Ronald Sackville AO QC

The Hon Ronald Sackville AO QC was a judge of the Federal Court of Australia from 1994 to 2008 and an acting Judge of Appeal of the Supreme Court of New South Wales from 2008 to 2019. Before his appointment to the Federal Court, Mr Sackville practised as a barrister in New South Wales and was appointed a Queen’s Counsel in 1991. Earlier in his career Mr Sackville was Professor and Dean of the Faculty of Law at the University of New South Wales.

Mr Sackville has chaired a number of bodies conducting public inquiries, including the Australian Government Commission of Inquiry into Poverty, the South Australian Royal Commission into the Non-Medical Use of Drugs, the New South Wales Law Reform Commission, and the Commonwealth Access to Justice Advisory Committee. Mr Sackville has also chaired the Victorian Accident Compensation Commission and has been a member of the Schools Commission. He was made an Officer of the Order of Australia in 2009 for service to the administration of the Australian judicial system, reform of federal and state law and legal education.

The Hon Roslyn Atkinson AO

The Hon Roslyn Atkinson AO was a judge of the Supreme Court of Queensland from 1998 to 2018. Ms Atkinson was the lead author of the Court's *Equal Treatment Benchbook*, the first in Australia. She served as Chair of the Queensland Indigenous Justice Committee with representatives from each of the state and federal courts in Queensland and was a member of the national Indigenous Justice Committee of the National Judicial College of Australia.

Ms Atkinson served as a member and inaugural President of the Queensland Anti-Discrimination Tribunal, was a Hearing Commissioner of the Human Rights and Equal Opportunity Commission (now the Australian Human Rights Commission) and was Chair of the Queensland Law Reform Commission from 2002 to 2014. In 2015, Ms Atkinson was appointed an Officer of the Order of Australia for distinguished service to the judiciary and to law reform in Queensland, through contributions to the legal profession and to promoting awareness of issues of injustice and inequality in Australia and internationally.

Ms Barbara Bennett PSM

Ms Barbara Bennett PSM brings to the Royal Commission 20 years' experience at senior levels in the federal public sector. She has held senior positions at both the Australian Government Department of Social Services and Department of Human Services, overseeing the development of policy and programs to support families, children, family safety, multicultural affairs and settlement services. Ms Bennett received a Public Service Medal in 2017 for outstanding public service in the area of social services.

Ms Bennett has personal experience of support and advocacy – for her mother, who has been living with quadriplegia for more than 20 years, and for her daughter, who was diagnosed with multiple sclerosis at age 12.

Dr Rhonda Galbally AC

As a woman with a lifelong disability, Dr Rhonda Galbally AC began working on disability rights in the 1980s at the Victorian Council for Social Services. Dr Galbally was then the CEO of the Sidney Myer Fund and the Myer Foundation. She was the founding CEO of a number of organisations, including the Australian Commission for the Future, the Australian International Health Institute, the Australian National Preventive Health Agency and Our Community. She also established the Victorian Health Promotion Foundation (VicHealth).

Dr Galbally chaired the Royal Women's Hospital and the National People with Disabilities and Carer Council and was the Independent Chair of the Review of Drugs, Poisons and Controlled Substances Legislation. She was a board member of the National Disability Insurance Agency and a member of the expert panel that developed the Victorian Charter of Human Rights and Responsibilities. Dr Galbally developed the National Disability and Carer Alliance that brought together people with disability, their families and support people with services to campaign for the National Disability Insurance Scheme (NDIS) by developing the Every Australian Counts campaign.

Ms Andrea Mason OAM

Ms Andrea Mason OAM is a Ngaanyatjarra and Karonie woman from Western Australia. She was the 2016 Telstra Australian Business Woman of the Year, 2017 Northern Territory Australian of the Year and 2017 Alice Springs Centralian Citizen of the Year. From 2009 to 2019 Ms Mason was the CEO of Ngaanyatjarra Pitjantjatjara Yankunytjatjara (NPY) Women's Council in central Australia. The organisation is acknowledged as one of the first Aboriginal organisations in Australia to prioritise support for Aboriginal people with disability, starting with a pilot project in 1993. In central Australia she has actively advocated for remote renal services in the NPY region, alcohol reform, women and family safety and innovative governance approaches for Indigenous leaders and organisations, including through the Empowered Communities model. She co-chaired the Prime Minister's Indigenous Advisory Council from 2017 to 2019, where she advised on key policy areas including the Closing the Gap Refresh. In 2018 Ms Mason received the Medal of the Order of Australia for services to the Indigenous community.

Ms Mason has built a reputation and career grounded in deep respect for the voices and collective determination of Australian First Nations peoples.

Mr Alastair McEwin AM

Born profoundly deaf, Mr Alastair McEwin AM is a long term disability advocate. For more than 25 years, Mr McEwin has worked across the private, government and non-government sectors, having held roles including Associate to the Hon Justice John von Doussa of the Federal Court, management consultant with Accenture, CEO of People with Disability Australia, and Executive Director of Community Legal Centres New South Wales. Immediately before his appointment to the Royal Commission, he was Australia's Disability Discrimination Commissioner, a position he commenced in July 2016. Addressing the issue of violence against people with disability was one of his six priority areas as Disability Discrimination Commissioner.

Mr McEwin also worked with Australian and international government and non-government organisations on the development of the text of the United Nations *Convention on the Rights of Persons with Disabilities*. Other roles Mr McEwin has held include President of the Deaf Society of New South Wales, coordinator of the World Federation of the Deaf Expert Group on Human Rights, and Chairperson of the Disability Council NSW, the official advisory body to the New South Wales Government on disability issues.

The Hon John Ryan AM

The Hon John Ryan AM experienced significant violence, neglect and abuse at home from a very young age. When he was 15 years old, he was removed from his family and placed in a boys' home for three years.

Mr Ryan was a public school teacher for a decade in Sydney's western suburbs. He was elected to the New South Wales Parliament in 1991, serving as Shadow Minister for Disability Services from 2003 to 2007. He chaired and participated in many parliamentary committees investigating a wide range of social justice issues.

After Parliament, Mr Ryan joined the New South Wales public sector, where he managed many reform projects aimed at strengthening human rights for people with disability. Mr Ryan was made a Member of the Order of Australia in 2018 for significant service to the Parliament of New South Wales and to public administration, particularly the development of accommodation policy for people with disability.

Conflicts of interest

The Australian public, and the disability community in particular, must have confidence that the Royal Commission will discharge its responsibilities independently, thoroughly and transparently.

There are well-established mechanisms to enable royal commissions to handle conflicts of interest or apprehensions of bias. The measures adopted by this Royal Commission include:

- The Chair will not authorise a Commissioner to participate in an aspect of the Royal Commission's work if that Commissioner has a conflict of interest in relation to that particular aspect of the Royal Commission's work, or if that Commissioner's involvement in that aspect of the Royal Commission's work may give rise to a reasonable apprehension of bias.
- The Chair will not authorise a Commissioner to participate in any aspect of a public hearing, or make findings following a hearing, if that Commissioner has a conflict of interest in respect of matters under consideration in that public hearing, or if a Commissioner's role in a public hearing may give rise to a reasonable apprehension of bias.
- Under no circumstances will a Commissioner participate in a hearing or in deliberations concerning matters that might bear in any way on that Commissioner's past conduct or the discharge of their responsibilities in a previous role.
- Until the Royal Commission completes its work, Commissioners will not
    - engage in other work, activities or advocacy, or
    - have financial interests in organisations including service providers, charities, non-government organisations or advocacy organisations

  without the prior approval of the Chair where that engagement and/or those financial interests may give rise to a potential conflict of interest.

Conflict of interest declarations by Commissioners can be found on the Royal Commission website.[6]

As noted above, in September 2019 the Commonwealth letters patent were amended[7] and the state letters patent were also subsequently amended.[8] The amendments clarify that the Chair has the power to give binding directions to other Commissioners.[9] These may include a direction that a Commissioner not participate in discussions on topics where they have an actual or potential conflict of interest or where their participation could give rise to a reasonable apprehension of bias.

Endnotes

1 *Letters Patent* (Cth), 4 April 2019.
2 *Letters Patent* (Cth), 4 April 2019 amended 13 September 2019, recitals.
3 Amended Letters Patent dated 13 September 2019 (Cth), (g).
4 Original Letters Patent dated: 17 April 2019 (NSW), 20 May 2019 (Tas), 4 June 2019 (Vic), 20 June 2019 (SA), 27 June 2019 (Qld) and 20 August 2019 (WA). Amended Letters Patent dated: 2 October 2019 (NSW), 10 October 2019 (Qld), 24 October 2019 (SA), 28 October 2019 (Tas), 29 October 2019 (WA) and 6 November 2019 (Vic). The relevant State Acts establishing the Royal Commission include the *Royal Commissions Act 1923* (NSW), *Commissions of Inquiry Act 1950* (Qld), *Royal Commissions Act 1917* (SA), *Commissions of Inquiry Act 1995* (Tas), *Inquiries Act 2014* (Vic) and *Royal Commissions Act 1968* (WA). The Letters Patent of each Royal Commission contain complementary terms of reference.
5 Amended Letters Patent dated: 2 October 2019 (NSW), 10 October 2019 (Qld), 24 October 2019 (SA), 28 October 2019 (Tas), 29 October 2019 (WA) and 6 November 2019 (Vic).
6 'Conflict of interest declarations', *Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability*, 19 June 2019. <https://disability.royalcommission.gov.au/publications/conflict-interest-declarations>
7 Amended Letters Patent dated 13 September 2019 (Cth).
8 Amended Letters Patent dated: 2 October 2019 (NSW), 10 October 2019 (Qld), 24 October 2019 (SA), 28 October 2019 (Tas), 29 October 2019 (WA) and 6 November 2019 (Vic).
9 Amended Letters Patent dated 13 September 2019 (Cth), (i).

Noah and Rosie*

Noah is almost a teenager and is homeschooled by his mother, Rosie. This isn't by choice; it's because Rosie believes there is no other safe option. In her submission, Rosie told us that Noah's experiences of specialist and mainstream schools have left him with significant trauma. Rosie believes the education system has let him down. 'They were supposed to protect, encourage and build self-esteem yet it crushed him.'

Before the bullying started at school Noah was a 'happy, witty, energetic, fun loving child,' said Rosie. Noah has autism spectrum disorder, attention deficit hyperactivity disorder and a mild intellectual disability.

His first school was a specialist school. When Noah complained of bullying the school said it was 'all in his head'. They continued to deny there was a problem even after Rosie witnessed Noah 'being held up against a fence with another child laying into him'.

Rosie moved Noah to a state school. However, not long after he started, the school complained that his behaviour was 'putting the class into lock down'. 'When I was called to come and collect him I found [Noah] locked in a small room,' said Rosie.

Rosie knew there had to be a trigger for Noah's behaviour because it wasn't happening at home, but the school blamed Noah and suspended him for two weeks. This would happen regularly and became a 'vicious cycle'.

'I know my child isn't perfect but [he] doesn't act out for attention or for the fun of it.'

When a teacher told Noah 'he was a horrible person and no wonder nobody likes him and that even your mother doesn't like you', it was obvious to Rosie that he was being bullied by the teacher and students.

Rosie told us the school asked her to medicate Noah, but she refused. Instead she enrolled him back into the specialist school, feeling she had no other choice.

When the behaviours started again Rosie decided to attend all excursions and events 'to figure out what the triggers were'. When students did things Noah didn't like he would say, 'stop it, I don't like it' or 'you're annoying me, leave me alone'. But Rosie saw the children 'ignore his pleas and keep doing what they were doing'.

When she brought this to the teacher's attention they suggested Noah be 'medicated so he was more accepting of other students' behavior'. Rosie reluctantly agreed and 'it was the worst decision I ever made.' Her happy, witty boy disappeared and Noah became 'a zombie'. He put on 40 kg and the behaviours didn't stop.

Noah continued to complain to Rosie that he was being bullied but that the teachers said he was the problem. He was often restrained and banned from attending outings and other events.

Rosie said that one day at a sporting event she watched a student hit Noah in the neck with a baseball bat. As she watched Noah struggle to breathe, the aide laughed and said Noah probably deserved it.

Rosie said she couldn't believe it – everyone had witnessed the incident, but still Noah was blamed. 'He was standing there doing nothing and [that child] just hit him in the neck with the bat.'

Noah refused to go to school for a while. When he did return, Rosie organised a meeting with the teacher so that Noah could tell her what he needed to help his behaviour. He asked for his desk to be moved to a corner and for partitions to be used so 'the kids wouldn't bother him and sit on his desk … eating and dropping their food over his desk or his stuff'.

They refused to accommodate his request and suggested they move his desk to the utility closet or outside. They also suggested he increase his dose of medication.

Rosie was horrified and told them 'he's not returning … it's illegal under the human rights act. It's child abuse. I'll homeschool him.' They threatened to report her if Noah didn't attend school while there was no homeschool registration in place.

'Do as you like,' Rosie said.

Noah is now homeschooled. Rosie told us he is off the medication and attends numerous group excursions each week without incident. He is also seeing a psychologist who is treating him for the trauma he suffers from the bullying he experienced at both primary schools.

*** Names changed and some details removed to protect people's identities. Narrative based on a submission to the Royal Commission.**

3. Our terms of reference

Key points

- The Royal Commission's terms of reference are broad, covering all forms of violence against, and abuse, neglect and exploitation of, people with disability in all settings and contexts in Australia.
- Our inquiry is framed by the human rights of people with disability, as outlined in the United Nations *Convention on the Rights of Persons with Disabilities* (*CRPD*).
- Our terms of reference require that we set up accessible and appropriate arrangements for people with disability, their families and support people to engage with the Royal Commission.

Introduction

This chapter outlines the scope of the Royal Commission's terms of reference. It discusses how our work is informed by human rights. It also highlights what makes this inquiry distinctive.

As noted in the previous chapter, the letters patent issued by the Governor-General of the Commonwealth of Australia on 4 April 2019 set out the terms of reference for this inquiry.[1]

The scope of our inquiry

The Royal Commission's terms of reference are extremely broad. We are directed to inquire into:

- what governments, institutions and the community should do to prevent and better protect people with disability from experiencing violence, abuse, neglect and exploitation in all settings and contexts[2]
- what governments, institutions and the community should do to achieve best practice to encourage reporting and investigation of, and responses to, violence against, and abuse, neglect and exploitation of, people with disability, including addressing failures in and impediments to such reporting, investigation and responses[3]
- what should be done to promote a more inclusive society that supports the independence of people with disability and their right to live free from violence, abuse, neglect and exploitation.[4]

While conducting our inquiry we are also required to consider:

- all aspects of quality and safety of services, including informal support, provided by governments, institutions and the community to people with disability, including the National Disability Insurance Scheme (NDIS) and the NDIS Quality and Safeguarding Framework[5]
- that the experiences of people with disability are multi-layered and influenced by experiences associated with their age, sex, gender, gender identity, sexual orientation, intersex status, ethnic origin or race[6]
- the particular experiences of First Nations people and culturally and linguistically diverse people with disability[7]
- the critical role that families, support people, advocates and the workforce play in providing care and support to people with disability[8]
- the findings and recommendations of previous relevant reports and inquiries[9]

- examples of best practice and innovative models of preventing, reporting, investigating and responding to violence against, and abuse, neglect and exploitation of, people with disability.[10]

We are not required to inquire into a particular matter to the extent that we are satisfied it has been, is being, or will be sufficiently and appropriately dealt with by the Royal Commission into Aged Care Quality and Safety (Aged Care Royal Commission), by another inquiry or investigation, or by criminal or civil proceedings.[11]

There is some overlap between our terms of reference and the terms of reference of the Aged Care Royal Commission. Both Royal Commissions have agreed on a protocol to ensure this overlap is handled appropriately. We review each submission we receive against the terms of reference of both Royal Commissions. Copies of submissions discussing people with disability aged over 65 and/or younger people with disability living in aged care facilities will be provided to the Aged Care Royal Commission, with the consent of the person who made the submission.

This Royal Commission is empowered by our terms of reference to make any recommendations we consider appropriate, including recommendations about necessary policy, legislative, administrative or structural reforms.[12]

We are to focus our inquiry and make recommendations on systemic issues, while being informed by individual experiences.[13]

We have started to examine the issues set out in the terms of reference. Emerging themes are discussed in Chapter 17, ‘Emerging themes and key issues’. Chapter 19, ‘Our future direction’, outlines what we will focus on during the time that remains.

The scope of our terms of reference means that we must investigate complex issues in many different areas. The letters patent require the inquiry to be completed within three years. The Royal Commission is directed to deliver an interim report by 30 October 2020[14] and a final report, including recommendations, by 29 April 2022.[15]

There has been a great number of past reports and inquiries on matters relevant to our terms of reference. It is an important part of our work to consider their findings and recommendations. Chapter 11, ‘Research and policy’, outlines the large research project under way to do this. Appendix B sets out the past reports and inquiries we have identified as most relevant to our terms of reference. References to, and some analysis of, past inquiries are made throughout this interim report.

Human rights inform our inquiry

The human rights of people with disability are an integral part of our inquiry. Our terms of reference specifically recognise that:

> people with disability are equal citizens and have the right to the full and equal enjoyment of all human rights and fundamental freedoms, including respect for their inherent dignity and individual autonomy.[16]

This includes the right of people with disability to live and participate in safe environments free from violence, abuse, neglect and exploitation.[17]

Our terms of reference also recognise that Australia has:

> international obligations to take appropriate legislative, administrative and other measures to promote the human rights of people with disability, including to protect people with disability from all forms of exploitation, violence and abuse under the *Convention on the Rights of Persons with Disabilities*.[18]

In Chapter 11, we outline research projects currently underway that will examine in detail the international human rights context in which the Royal Commission operates, and Australia's level of compliance with its obligations under the *CRPD.*

We explain our current thinking about the meaning of a human rights approach to the work of the Royal Commission in Chapter 16, 'Our theoretical approaches'.

What makes this inquiry distinctive

This Royal Commission is often compared to other royal commissions, but it has two distinctive, if not unique, features.

The first is the extraordinary breadth of the terms of reference. As noted, we are required to look at all forms of violence against, and abuse, neglect and exploitation of, people with disability **'in all settings and contexts'**.[19] By contrast, other recent royal commissions have focused on issues arising in specific settings. For example, the Royal Commission into Institutional Responses to Child Sexual Abuse, which took five years to complete, focused on the responses of institutions to child sexual abuse. The Aged Care Royal Commission is looking specifically at aged care services and facilities.

The breadth of the terms of reference is evident from the subject matter of the public hearings that we have already held and that we plan to hold over the remainder of 2020, subject to any significant change in circumstances.[20] Other chapters in this interim report also illustrate the range of issues that fall within the terms of reference.

The scope of our work presents very significant challenges. Each setting in which violence against, and abuse, neglect and exploitation of, people with disability occurs presents different, although related, factual and policy issues. The Royal Commission therefore must draw on and conduct research in a variety of disciplines and seek the help of specialists, including people with disability, with expertise and experience in many different fields.

We are also conscious that the life experiences of people with disability cannot be neatly compartmentalised into categories or domains. What we have heard so far suggests that neglect or discrimination against people with disability in, for example, the health or education systems, may have consequences in other areas of their lives. The Royal Commission must explore these life-course issues.

The second distinctive feature of the Royal Commission's work arises from the recognition in the terms of reference that people with disability should be central to the processes that inform best practice decision making on what Australian governments and others can do to prevent and respond to violence against, and abuse, neglect and exploitation of, people with disability.[21] This recognition underpins our commitment to ensuring that people with disability are central to our work.

The terms of reference build on this recognition by requiring the Royal Commission to establish accessible and appropriate arrangements for people with disability, their families and support people and others to engage with the inquiry, provide evidence and share information about their experiences.[22]

We are conscious that people with disability who have experienced violence, abuse, neglect or exploitation may have been exposed to or experienced trauma. Our approach aims to minimise, to the greatest extent possible, the risk of re-traumatising people engaging with the inquiry.

We are committed to putting accessibility, inclusion and trauma-informed approaches at the centre of our work. For details on how we are doing this, see Chapter 5, 'Our organisation' and Chapter 6, 'Support for people engaging with the Royal Commission'.

Endnotes

1 *Letters Patent* (Cth), 4 April 2019 amended 13 September 2019.
2 *Letters Patent* (Cth), 4 April 2019 amended 13 September 2019, (a).
3 *Letters Patent* (Cth), 4 April 2019 amended 13 September 2019, (b).
4 *Letters Patent* (Cth), 4 April 2019 amended 13 September 2019, (c).
5 *Letters Patent* (Cth), 4 April 2019 amended 13 September 2019, (f).
6 *Letters Patent* (Cth), 4 April 2019 amended 13 September 2019, (g).
7 *Letters Patent* (Cth), 4 April 2019 amended 13 September 2019, (g).
8 *Letters Patent* (Cth), 4 April 2019 amended 13 September 2019, (h).
9 *Letters Patent* (Cth), 4 April 2019 amended 13 September 2019, (j).
10 *Letters Patent* (Cth), 4 April 2019 amended 13 September 2019, (i).
11 *Letters Patent* (Cth), 4 April 2019 amended 13 September 2019.
12 *Letters Patent* (Cth), 4 April 2019 amended 13 September 2019, recitals.
13 *Letters Patent* (Cth), 4 April 2019 amended 13 September 2019, (l).
14 *Letters Patent* (Cth), 4 April 2019 amended 13 September 2019, (r).
15 *Letters Patent* (Cth), 4 April 2019 amended 13 September 2019, (s).
16 *Letters Patent* (Cth), 4 April 2019 amended 13 September 2019, recitals.
17 *Letters Patent* (Cth), 4 April 2019 amended 13 September 2019, recitals.
18 *Letters Patent* (Cth), 4 April 2019 amended 13 September 2019, recitals.
19 *Letters Patent* (Cth), 4 April 2019 amended 13 September 2019, (a).
20 Information about the Royal Commission’s public hearings is available on our website: ‘Public hearings’, *Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability*. <https://disability.royalcommission.gov.au/public-hearings>
21 *Letters Patent* (Cth), 4 April 2019 amended 13 September 2019, recitals.
22 *Letters Patent* (Cth), 4 April 2019 amended 13 September 2019, (k).

Jennifer*

Jennifer has a disability and is also a support person for a friend with disability.

In her submission to us she said she has seen for herself, during recent inpatient hospital treatment, that health professionals 'will lie by omission of information at every chance they get in order to comply with their workplace policies and treatment practices':

> Doctors and nurses have shown that they will leave out relevant information when seeking patient consent for treatment.
>
> They have also shown that they will neglect to inform the patient of their health progress if they feel it may reflect badly on medical procedures they have used.
>
> Further doctors will threaten patients with involuntary treatment orders if the patient questions their practices or tries to ask for clarifying information about their treatment.

Jennifer told us that in her experience medical staff will often dismiss the concerns or questions of patients with disability in the belief that 'they know better'. She said they routinely fail to provide clear information at a patient's communication level.

She also said that unless a patient has someone aggressively advocating for them, medical practitioners will 'simply railroad a disabled patient into their own goals'.

*** Name changed and some details removed to protect people's identities. Narrative based on a submission to the Royal Commission.**

4. Nature and powers of the Royal Commission

Key points

- The Royal Commissions' terms of reference, together with the *Royal Commissions Act 1902* (Cth), govern the conduct of its investigations and hearings.
- The *Royal Commissions Act* gives the Royal Commission a number of powers, including 'coercive powers' that enable it to require individuals, organisations or governments to provide documents or information to it.
- The *Royal Commissions Act* provides protections for the people the Royal Commission compels to provide it with documents or information.
- A person can ask the Royal Commission to issue them with a compulsory notice to produce their submission, so the protections in the *Royal Commissions Act* will apply to them.
- During the life of its inquiry, the Royal Commission can ensure that the information it receives is kept confidential.
- Except in limited circumstances, information provided to the Royal Commission in private sessions will remain confidential even after the inquiry ends.
- The Royal Commission has asked the Australian Government to introduce legislation to ensure that information the Royal Commission holds about a person's experience of violence, abuse, neglect and/or exploitation remains confidential after the inquiry ends.
- In limited circumstances, the Royal Commission may decide it is appropriate to pass on information to the police or another authority, including if it is about a criminal offence.

Introduction

This chapter provides an overview of the nature and powers of a royal commission, and in particular, of this Royal Commission. It explains how the information and documents we collect can be protected from disclosure, and how in certain circumstances the *Royal Commissions Act 1902* (Cth) can protect people who want to engage with the Royal Commission, including people with disability, their families and supporters, or people who identify as 'whistleblowers'.

This chapter also describes the Royal Commission's obligations under its terms of reference to communicate information or evidence to other authorities, including to the police or another royal commission.

The *Royal Commissions Act*

As outlined in previous chapters, the Royal Commission was established by letters patent issued under the *Royal Commissions Act*.[1] This legislation, together with its state counterparts,[2] confers important powers on the Royal Commission and, combined with the terms of reference, governs the conduct of our investigations and hearings. For example, the *Royal Commissions Act*:

- empowers the Royal Commission to compel persons[3] to produce documents and to give evidence at a public hearing[4]
- authorises the Royal Commission to apply to a judge for a warrant enabling police officers or other persons to search premises and seize articles connected with an investigation[5]
- provides for the Attorney-General to appoint counsel to assist the Royal Commission, including by presenting evidence and examining witnesses at hearings[6]
- authorises the Chair of the Royal Commission to determine which Commissioners will participate in a particular hearing[7]
- largely removes the privilege against self-incrimination, that is, the right to refuse to answer questions on the basis that to do so might incriminate that person in the commission of an offence[8]
- makes it a criminal offence to act deliberately in certain ways that adversely affect the work of the Royal Commission, or have an adverse effect on a person who has given information or evidence to the Royal Commission.[9]

At the request of this Royal Commission, the Australian Parliament amended the *Royal Commissions Act* in September 2019 to enable us to conduct private sessions.[10] This means that people who want to share their experiences with a Commissioner can do so in a confidential and informal setting.

The Chair can now authorise Commissioners to hold private sessions to obtain information about matters into which the Royal Commission is inquiring.[11] The Chair has stated that in exercising this power, the overriding consideration will be the safety, security and comfort of the person wanting to participate in a private session. Under no circumstances will anyone be asked to share their experiences with a particular Commissioner if they do not feel comfortable doing so. Chapter 10, 'Private sessions', contains further information about private sessions in this Royal Commission.

The nature of a royal commission

Many people think of a royal commission as a court that exercises judicial power. This is understandable, because a royal commission does have some of the characteristics of a court. It is independent of government, holds public hearings, can compel the production of documents and can require people to attend hearings and give evidence.

However, a royal commission is not a court. The critical difference is that, unlike a court, a royal commission cannot make binding decisions that have the force of law. A royal commission can publish reports that, for example, include recommendations to prosecute, or which propose reforms to provide compensation for people who have suffered harm. However, it is up to others to decide whether or not to accept the recommendations. It follows, for example, that a royal commission cannot convict a person of a criminal offence and cannot make an order requiring someone to pay compensation to a victim of misconduct.

A royal commissioner:

- is appointed on behalf of the government to carry out an investigation or inquiry
- is required to present a report to government about the results of their investigation or inquiry, and
- in their report makes findings of fact and makes non-binding recommendations to government based on those findings.[12]

The principles that govern any royal commission go beyond the limited provisions of the *Royal Commissions Act*. A royal commission has a wide discretion as to how it carries out its inquiry, but it must ensure that it does so within its legitimate powers and role. It must act in accordance with the general law, except where that general law has been modified by legislation.

Subject to the terms of reference, commissioners are bound to keep an open mind as they conduct their inquiry and consider evidence, submissions and other material that can properly be taken into account. This means that a royal commission is required to consider all views expressed in the information and evidence it receives.

A royal commission must also ensure that it observes procedural fairness (sometimes described as the rules of natural justice). This means that a royal commission should only make or publish findings that someone has acted improperly when that person has been given a fair opportunity to understand and respond to the allegations made against them. One of the reasons for this requirement is that although the publication of an adverse finding will not usually have any immediate legal consequences, it may, at the least, seriously affect the reputation and standing of the person or organisation named in the report.

Power to compel production of information and documents

The *Royal Commissions Act* gives royal commissions certain coercive powers. State legislation confers similar powers.

The Royal Commission can require a person to:

- provide it with documents or things in response to a compulsory notice to produce[13]
- give information or a statement in writing in response to a compulsory notice[14]
- appear before the Royal Commission to give evidence under oath or affirmation.[15]

When a royal commission exercises its coercive powers, such as by issuing a compulsory notice, it enlivens certain protections in the *Royal Commissions Act* (see 'Protections under the *Royal Commissions Act*' below).

In certain circumstances, this Royal Commission will use its coercive powers to make these protections available to people who wish to engage with us. This could include, for example, when a person with disability or a person who identifies as a whistleblower wants to share their experiences with us but has genuine concerns about possible recriminations or even legal consequences if they identify individuals or organisations who have acted improperly or inappropriately.

As at 31 July 2020, the Royal Commission has, at the request of people seeking those protections, issued 34 notices to produce for submissions. (The Royal Commission's submissions process is described in detail in Chapter 8, 'Submissions'.)

There are a number of external supports available for people engaging with the Royal Commission, including when they are providing information in the ways described in this chapter. Those supports include access to a free legal advisory service and legal financial assistance, and are outlined in more detail in Chapter 6, 'Support for people engaging with the Royal Commission'.

Protections under the *Royal Commissions Act*

Senior Counsel Assisting the Royal Commission have, during our public hearings, repeatedly emphasised the importance of protecting witnesses. They have specifically recognised the protections available under the *Royal Commissions Act* for witnesses and for individuals responding to compulsory notices.[16]

Those protections take the form of a number of offences in the *Royal Commissions Act*.[17] These include:

- several offences relating to interference by bribery, fraud or otherwise with people who are responding to compulsory notices[18]
- the offence of causing injury (including loss, damage or disadvantage) to a person appearing as a witness before, or producing documents or things to, the Royal Commission in response to a compulsory notice[19]
- the offence of an employer dismissing or causing prejudice to an employee producing documents or things in response to a compulsory notice.[20]

These are serious criminal offences, carrying maximum penalties of between one and five years in prison.

The Royal Commission will assess and, where appropriate, refer to the Australian Federal Police, any allegation of recriminations against a person who has provided information or a statement in response to a compulsory notice, or who has been called to or given evidence before the Royal Commission. This includes where a person, for example:

- has been pressured not to speak to the Royal Commission
- has been offered any kind of benefit not to tell the truth when giving evidence before the Royal Commission, or not to produce information or documents to the Royal Commission
- has been sued because they gave information to the Royal Commission in breach of a confidentiality or non-disclosure clause in a contract or agreement
- has been sued for making a defamatory statement in a submission or statement produced or made to the Royal Commission
- has been sacked from, or suffered prejudice in, their employment because they gave information to the Royal Commission about their employer or place of employment
- might identify as a whistleblower.

The *Royal Commissions Act* also provides that any statement or disclosure made in writing by an individual in response to a compulsory notice, or made in the course of giving evidence before the Royal Commission, is not admissible as evidence against them in any civil or criminal proceedings in any Commonwealth, state or territory court.[21] This protection is particularly important if a person is concerned that their statement or disclosure might be defamatory.

The same protections apply to a person who attends or has requested to attend a private session,[22] and to any information given by a person at or for the purposes of a private session.[23] We discuss protection of private sessions information in more detail later in this chapter.

Confidentiality of information

We recognise that concerns about the Royal Commission's capacity to ensure the confidentiality of information provided to it are a significant obstacle for some people who would like to engage with us.

With limited exceptions, we can ensure that any information or documents provided to us by people with disability, their families, supporters, or any other person, remain confidential during the life of the Royal Commission. Those exceptions include:

- where the person consents to the disclosure of their information or documents
- where we are legally obliged to disclose the information, for example if mandatory reporting laws apply
- where the Royal Commission decides it is appropriate to give the information to the police because, for example, it relates to a breach of a criminal law.[24]

Subject to those same exceptions, and to the observation of procedural fairness, we are also obliged to ensure that information or documents provided to the Royal Commission in response to compulsory notices remain confidential at least until we deliver our final report.[25]

Importantly, the Royal Commission:

- can resist demands by third parties for access to information provided in submissions or in other documents produced in response to compulsory notices, including demands made by summons or subpoena
- is exempt from the operation of freedom of information legislation.[26]

Non-publication directions

The *Royal Commissions Act*[27] also gives the Royal Commission the power to:

- order that evidence be taken in private (a private hearing)[28]
- direct that any evidence given before it, or information produced before or delivered to it, including in response to a compulsory notice, not be published (a non-publication direction)[29]

- direct that information that might allow for the identification of a person who has given evidence before the Royal Commission not be published (a pseudonym direction).[30]

If the Royal Commission makes a non-publication or pseudonym direction, the information the direction applies to cannot be published unless and until the Royal Commission makes a further order.

Confidentiality after the Royal Commission ends

As noted, information and documents produced to the Royal Commission will, where requested and/or appropriate, remain confidential for the life of the Royal Commission. This includes submissions provided in response to compulsory notices.

However, with the exception of private sessions information (see below), we are, as at 31 July 2020, unable to guarantee that information we hold will remain confidential after the Royal Commission delivers its final report to the Australian Government (currently scheduled for April 2022).

After the Royal Commission ends, our records (including submissions and information provided in response to compulsory notices) will be held by the Australian Government Attorney-General's Department and then by the National Archives of Australia.[31] The records may then be sought under court-issued subpoenas or other compulsory processes. They may also be the subject of freedom of information requests, although disclosure of information in response to a request under freedom of information legislation may be subject to various exceptions, including that disclosure is not in the public interest.

We are aware that if people with disability, their families, supporters, or people who identify as whistleblowers do not feel confident that the information they provide to the Royal Commission can remain confidential after the Royal Commission ends, our inquiry may be limited in its reach. This is particularly so because while we will make every effort to do so, we may not be able to offer a private session to every person who requests one.

We therefore asked the Australian Government to introduce legislation to ensure that information we hold about a person's experience of violence, abuse, neglect and/or exploitation that might identify them has the same level of protection as information given at or for a private session; that is, it cannot be disclosed, even after the Royal Commission ends.[32] As at 31 July 2020, it remained a matter for the Australian Government to decide.

Private session information

A private session is a voluntary meeting between an individual and a Commissioner during which the individual can share information in a safe and confidential environment.

A private session is not a hearing of the Royal Commission and a person attending a private session is not a witness. When people provide information at private sessions, they are not giving evidence to the Royal Commission[33] (see Chapter 10 for more information).

Private sessions are the main way in which the Royal Commission can guarantee that information will remain confidential, both during and after the Royal Commission. This is because the *Royal Commissions Act* makes it an offence for a person (other than the person who gave the information) to record, use or disclose information provided at, or for the purposes of, a private session ('private sessions information').[34] This protection extends beyond the life of the Royal Commission.

Private sessions information is protected from disclosure even if that disclosure is required by another law.[35] For example, private sessions information cannot be disclosed, either during or after the life of the Royal Commission, in response to:

- a court-issued subpoena or other compulsory process
- a freedom of information application.

A record containing private sessions information cannot be accessed in the National Archives of Australia until 99 years after it was created.[36]

However, it is important to note that there are some exceptions to these prohibitions, and that some private sessions information may be used or disclosed in very limited circumstances. They are:[37]

- when the use or disclosure is for the purpose of the Royal Commission performing its functions or duties, or exercising its powers
- if the person consents to their information being used or disclosed
- if the disclosure is to another authority and is authorised by section 6P of the *Royal Commissions Act* (see 'The Royal Commission's power to communicate information' later in this chapter)
- if the information has also been given as evidence to the Royal Commission or produced in response to a compulsory notice, or if it has been de-identified, it can be included in our reports or recommendations[38]
- when custody of the information is transferred as part of the Royal Commission's records to the Australian Government Attorney-General's Department at the end of the Royal Commission. Once custody of the information has transferred, the Attorney-General's Department is responsible for its protection against use or disclosure.[39]

Communicating information

During the life of the Royal Commission, some of the information we will receive will include allegations that an entity or person has breached a criminal or civil law, or will relate to the work of another royal commission.

The Royal Commission is not a law enforcement body and it is not our function to determine such allegations. However, our terms of reference require us to:[40]

- ensure that we can communicate information, documents, or evidence that would, for example, enable the timely investigation and prosecution of offences, or which would assist the Royal Commission into Aged Care Quality and Safety
- ensure that the way in which we deal with evidence identifying a person as having been subjected to violence, abuse, neglect or exploitation will not prejudice current or future criminal or civil investigations or proceedings, or other inquiries.

Therefore, we have established an Investigations team, which considers information and advises the Royal Commission about the appropriateness of communicating that information to other authorities under section 6P of the *Royal Commissions Act*. As described below, the Investigations team also liaises with law enforcement agencies across Australia to ensure that the Royal Commission's work does not interfere with current or future criminal investigations or proceedings.

The Royal Commission's power to communicate information

Section 6P(1) of the *Royal Commissions Act* gives the Royal Commission the power to communicate to certain authorities (including the police)[41] any information or evidence that we collect during the inquiry that relates or may relate to a breach of a Commonwealth, state or territory law for which a person could be liable for a criminal or civil penalty.[42]

Section 6P of the *Royal Commissions Act* also allows the Royal Commission to communicate information or evidence to another royal commission, and to other specified authorities if the information or evidence relates to their functions or responsibilities.[43] Such authorities or royal commissions may then make a record of, use or disclose that information or evidence in the exercise of their powers or functions.[44]

The Royal Commission may communicate this information to the authorities listed in section 6P of the *Royal Commissions Act* if it decides that it is appropriate to do so. This power can be exercised even if the information was provided to us confidentially, in response to a compulsory notice, or at or for the purposes of a private session.[45]

Our Investigations team

Our Investigations team was established in March 2020. As at 31 July 2020, it included officers and an analyst on secondment from the Australian Federal Police.

The Investigations team reviews, analyses, assesses and collates information and evidence gathered by the Royal Commission about reported instances of violence against, and abuse, neglect and exploitation of, people with disability. It assesses whether that information or evidence relates or may relate to a breach of a Commonwealth, state or territory law for which a person could be liable for a criminal or civil penalty. It makes recommendations to the Chair and Commissioners about whether it is appropriate to communicate such information or evidence to another authority or authorities under section 6P of the *Royal Commissions Act.*

The Investigations team has established contacts with law enforcement agencies in each Australian state and territory to:

- facilitate communication between the Royal Commission and those agencies under section 6P of the *Royal Commissions Act*
- communicate with those agencies to ensure that the work of the Royal Commission will not prejudice current or future criminal or civil investigations or proceedings.

Endnotes

1 *Royal Commissions Act 1902* (Cth).
2 The relevant state legislation establishing the Royal Commission are: *Royal Commissions Act 1923* (NSW), *Commissions of Inquiry Act 1950* (Qld), *Royal Commissions Act 1917* (SA), *Commissions of Inquiry Act 1995* (Tas), *Inquiries Act 2014* (Vic) and *Royal Commissions Act 1968* (WA).
3 Includes an individual, non-government organisation, or a government organisation.
4 *Royal Commissions Act 1902* (Cth), s 2.
5 *Royal Commissions Act 1902* (Cth), ss 4 and 5.
6 *Royal Commissions Act 1902* (Cth), s 6FA.
7 *Royal Commissions Act 1902* (Cth), s 2.
8 *Royal Commissions Act 1902* (Cth), s 6A.
9 *Royal Commissions Act 1902* (Cth), ss 3, 6AB and 6H-6O.
10 The *Royal Commissions Act 1902* (Cth) was amended by the *Royal Commissions Amendment (Private Sessions) Act 2019* (Cth).
11 *Royal Commissions Act 1902* (Cth) s 6OB.
12 Peter M Hall, *Investigating corruption and misconduct in public office: Commissions of Inquiry – Powers and Procedures*, Thomson Reuters, 2nd Ed, 2019, p 450. These remarks are equally applicable to a multi-member royal commission.
13 A notice to produce can be issued under s 2(3A) of the *Royal Commissions Act 1902* (Cth) and 'person' includes an individual, non-government organisation, or a government organisation. Similar powers also exist under s 8 of the *Royal Commissions Act 1923* (NSW), s 5(1)(b) of the *Commissions of Inquiry Act 1950* (Qld), s 10(c) of the *Royal Commissions Act 1917* (SA), s 22(1) of the *Commissions of Inquiry Act 1995* (Tas), s 17(1) of the *Inquiries Act 2014* (Vic), and s 8B(1)(b) of the *Royal Commissions Act 1968* (WA).
14 Not all state royal commission acts give the Royal Commission this power. A notice to give information or a statement in writing can be issued under s 2(3C) of the *Royal Commissions Act 1902* (Cth) where 'person' includes an individual, non-government organisation, or a government organisation. Similar powers also exist under s 5(1)(d) of the *Commissions of Inquiry Act 1950* (Qld), and s 8A(2) of the *Royal Commissions Act 1968* (WA).
15 *Royal Commissions Act 1902* (Cth) ss 2(1) and 2(3), *Royal Commissions Act 1923* (NSW) s 8, *Commissions of Inquiry Act 1950* (Qld) s 5(1)(a), *Royal Commissions Act 1917* (SA) s 10(b), *Commissions of Inquiry Act 1995* (Tas) s 22(1), *Inquiries Act 2014* (Vic) s 17(2), *Royal Commissions Act 1968* (WA) s 9.
16 Transcript, Senior Counsel Assisting Dr Kerri Mellifont QC, Public Hearing 2, Townsville, 7 November 2019, P-332 [24–25]; Transcript, Senior Counsel Assisting Kate Eastman SC, Public Hearing 3, Melbourne, 2 December 2019, P-15 [21–37]; Transcript, Senior Counsel Assisting Kate Eastman SC, Public Hearing 4, Sydney, 18 February 2020, P-17 [15–23].
17 Similar offence provisions appear in some, but not all of the state legislation establishing the Royal Commission.
18 *Royal Commissions Act 1902* (Cth) ss 6I, 6J, and 6L.
19 *Royal Commissions Act 1902* (Cth) s 6M.
20 *Royal Commissions Act 1902* (Cth) s 6N.
21 *Royal Commissions Act 1902* (Cth) s 6DD. Note that this protection does not apply to court proceedings for an offence against the *Royal Commissions Act 1902* (Cth). Similar provisions appear in all of the state legislation establishing the Royal Commission.
22 *Royal Commissions Act 1902* (Cth) s 6OC(5)(a).
23 *Royal Commissions Act 1902* (Cth) ss 6OC(5)(b) and (c) and 6OE.
24 *Royal Commissions Act 1902* (Cth) s 6P.

25 See Johns v Australian Securities and Investments Commission (1993) 178 CLR 408.

26 See for example, Freedom of Information Act 1982 (Cth), ss 4 and 11; Government Information (Public Access) Act 2009 (NSW), sch 4.

27 Similar provisions appear in all of the state legislation establishing the Royal Commission.

28 *Royal Commissions Act 1902* (Cth) s 6D(5).

29 *Royal Commissions Act 1902* (Cth) s 6D(3).

30 *Royal Commissions Act 1902* (Cth) s 6D(3)(c).

31 *Royal Commissions Act 1902* (Cth) s 9 and *Royal Commissions Regulations 2019* (Cth) para 10.

32 See for example, s 6ON of the *Royal Commissions Act 1902* (Cth), which makes special provision for information relating to a person's experience of abuse given to the Royal Commission into Institutional Reponses to Child Sexual Abuse. Section 6ON ensures the long term confidentiality of that information by treating that information as if it had been given at a private session.

33 *Royal Commissions Act 1902* (Cth) s 6OC(1) and (2).

34 *Royal Commissions Act 1902* (Cth) s 6OH.

35 *Royal Commissions Act 1902* (Cth) s 6OL.

36 *Royal Commissions Act 1902* (Cth) s 6OM.

37 *Royal Commissions Act 1902* (Cth) s 6OH.

38 See s 6OJ of the *Royal Commissions Act 1902* (Cth).

39 See s 9 of the *Royal Commissions Act 1902* (Cth).

40 See paragraphs (m) and (n) of the Letters Patent of the Commonwealth and States dated: 4 April 2019 (amended 13 September 2019) (Cth), 17 April 2019 (amended 2 October 2019) (NSW), 20 May 2019 (amended 28 October 2019) (Tas), 4 June 2019 (amended 6 November 2019) (Vic), 20 June 2019 (amended 24 October 2019) (SA), 27 June 2019 (amended 10 October 2019) (Qld), and 20 August 2019 (amended 29 October 2019) (WA).

41 The bodies to which the Royal Commission may communicate information under s 6P(1) of the *Royal Commissions Act 1902* (Cth) are: the Attorney-General of the Commonwealth, of a State of the Australian Capital Territory or of the Northern Territory; the Director of Public Prosecutions; a Special Prosecutor appointed under the Special Prosecutors Act 1982 (Cth); the Commissioner of the Australian Federal Police or of the Police Force of a State or of the Northern Territory; or the authority or person responsible for the administration or enforcement of the law of which there may have been a breach.

42 *Royal Commissions Act 1902* (Cth) s 6P(1A).

43 *Royal Commissions Act 1902* (Cth) ss 6P(2), (2A) and (2B). Those other authorities are the Chief Executive Officer of the Australian Criminal Intelligence Commission and the Integrity Commissioner.

44 *Royal Commissions Act 1902* (Cth) ss 6P(2C).

45 *Royal Commissions Act 1902* (Cth) ss 6P and 6OH(c)(ii).

Ben, Will and Jenny*

Will and Jenny Malone are guardians of their foster son, Ben, who is autistic and has language difficulties and physical disabilities. Ben lives in a group home.

The Malones told us in their submission that there has been trouble at Ben's group home. They said that Ben seems to be okay but at least two female residents have been assaulted and bullied by another. One of the two women, a longstanding resident, recently moved out – which the Malones think is due to the seriousness of the physical assault, bullying and harassment she was experiencing.

The Malones said they believe that bullying and harassment between residents has happened before in this house. They attributed the increased risk of violence and abuse there to poor management and supervision by the supported independent living (SIL) provider, and poor selection of residents.

When the woman who had been bullied moved out, the Malones said, the provider told residents' families that it would work with the relevant state department to select a new resident and would advocate on behalf of the current residents to ensure the new resident was compatible.

The Malones told us that a situation where neither the residents nor their guardians are directly involved in the selection process is unacceptable to them. They say it infringes the rights of people with disability to have the opportunity to choose their place of residence and who they live with.

Will says:

> There have been two inappropriate placements, which have both resulted in physical assault and ongoing bullying and harassment of female residents and support staff.
>
> As parents and guardians we do not want a repeat of these conditions, and therefore want to be involved in the selection process, as I believe is our right under NDIS principles.

The Malones told us they had been successful on this occasion in making sure the resident families would be involved in the selection process, but they expressed concern that this doesn't seem to be standard practice or a mandatory requirement.

They said they are concerned that the NDIS does not define clearly the services and role of SIL providers. They have raised a range of questions regarding SIL providers, and hope the spotlight of the Royal Commission will bring these issues into focus.

*** Names changed and some details removed to protect people's identities. Narrative based on a submission to the Royal Commission.**

5. Our organisation

Key points

- The Royal Commission is guided by the principles of equality, inclusion, respect, dignity, autonomy, aspiration and self-determination.
- As at 31 July 2020, 198 staff support the Chair and Commissioners and we have a range of strategies in place to ensure we prioritise recruitment of people with disability.
- We have applied universal design principles to ensure our premises are inclusive and accessible, including a purpose-built hearing room in Brisbane.

Introduction

The Royal Commission is committed to ensuring that our inquiry is inclusive and accessible – a commitment that extends to our staff and workplace.

This chapter outlines what we have done so far to meet this commitment. It describes:

- our values
- our Accessibility and Inclusion Strategy
- how we recruit and support staff
- the measures taken to ensure accessibility and inclusion at public hearings and other events, and in our offices.

It also provides an overview of the Royal Commission's finances.

Our values

In undertaking our work we are guided by the following values:

- **Equality:** People with disability are equal citizens, who have the right to the full and equal enjoyment of all human rights and fundamental freedoms, including respect for their inherent dignity and individual autonomy. They have the same rights as other members of Australian society to live and participate in safe environments free from violence, abuse, neglect and exploitation.
- **Inclusion:** We seek to promote a society that facilitates the full and effective participation and inclusion of people with disability. We are mindful people with disability often face barriers to inclusion. We will provide people with a range of ways to engage with us so they can select the one that best suits them.
- **Respect:** We respect people with disability and their rights and freedoms.
- **Dignity:** We accept the inherent dignity and rights of all people.
- **Autonomy:** We respect the independence and autonomy of people with disability, including the equal right and freedom to make their own choices.
- **Aspiration:** We acknowledge the strengths and contributions of people with disability. Our approaches and work will recognise the right and ability of people with disability to aspire to the lives they want to lead in all aspects and at all stages of their lives.
- **Self-determination:** We will carry out our work in a way that is consistent with the *United Nations Declaration on the Rights of Indigenous Peoples*.[1] We acknowledge the importance of free, prior and informed consent and commit to ensuring that First Nations people, communities and organisations can decide their levels and methods of engagement with the Royal Commission.

We take a trauma-informed approach to our inquiry. This means that we must understand the physical, social and emotional impacts of violence and other forms of trauma and integrate this understanding into our work. We aim to minimise re-traumatisation and to encourage people to feel physically, emotionally and culturally safe when engaging with us. We say more about our trauma-informed approach in Chapter 6, ‘Support for people engaging with the Royal Commission’.

Accessibility and inclusion

The Royal Commission’s Accessibility and Inclusion Strategy guides how the Royal Commission operates as an inclusive and accessible organisation. This includes how we communicate with people with disability and the wider community, recruit and train staff and how we select and set up premises, hearing rooms and venues for public events. This is explained in more detail below.

The Strategy also guides how we undertake our external work, such as engaging and communicating with stakeholders. Part B, ‘How we do our work’ outlines how we have applied inclusive and accessible practices in all parts of our work, including our community engagement and public hearings.

We developed the strategy in consultation with people with disability and advocacy groups. We will adapt the strategy and our practices as we learn what can be done more appropriately and effectively.

The strategy is available on our website.[2]

Our staff

The Chair and six Commissioners are supported by 198 staff, as at 31 July 2020. (See Chapter 2, ‘Our Chair and Commissioners’ for more information on the Chair and Commissioners.) The office of the Royal Commission is led by the Official Secretary Paul Cronan AM, who is supported by seven senior executives:

- Emma Appleton
- Cain Beckett
- Joanna Blair
- Joanna Carey
- Andras Markus
- Marianne Peterswald
- Megan Shipley.

We acknowledge the contribution of Toni Pirani during the setting up of the Royal Commission.

We are committed to recruiting skilled people and prioritise recruiting people with disability.

The Australian Public Service Commission’s Affirmative Measures guidelines and its RecruitAbility scheme apply to all roles with the Royal Commission.[3] These initiatives are designed to promote employment opportunities for, and address the under representation in employment of, people with disability. Under s 27 of the *Australian Public Service Commissioner’s Directions 2016*, our Affirmative Measures employment register is only open to people with disability.[4] As at 31 July 2020, we have engaged 19 staff from the Affirmative Measures register.

We have also identified recruitment firms with strong disability/diversity credentials and/or certification to partner with, and sought their commitment to have people with disability front of mind when recruiting staff for the Royal Commission.

A number of roles across the Royal Commission require knowledge and expertise of issues relevant to First Nations peoples and the ability to communicate sensitively and effectively with First Nations people. First Nations staff are employed across the Royal Commission to ensure their expertise is applied to our work. For example, our Intake, Counselling and Support Services team includes male and female First Nations counsellors, and we employ First Nations engagement officers and First Nations policy staff. Recruitment firms have been used to seek suitable First Nations candidates.

Our staff members include three senior advisors, people with disability who are experts in their field. They are:

- Emeritus Professor Ron McCallum AO, who provides legal research expertise and guidance on international human rights
- Associate Professor Lorna Hallahan, who provides academic and research expertise
- Maurice Corcoran AM, who provides expertise on policy issues and on engaging with people with disability.

Table 5.1 gives a snapshot of our staff, including diversity statistics.

Table 5.1: Royal Commission staff snapshot, at 31 July 2020

	Number	Percentage
Total	**198**	**100.0%**
Location		
Sydney	113	57.1%
Brisbane	51	25.7%
Canberra	32	16.2%
Other	2	1.0%
Diversity [a]		
Disability	22	11.1%
First Nations	11	5.6%

[a] Diversity rates are based on voluntary self-reporting and may not reflect total numbers.

Counsel Assisting

As at 31 July 2020, eight Counsel are assisting the Royal Commission, having been appointed by the Attorney-General to do so. They are:

- Dr Kerri Mellifont QC
- Kate Eastman SC
- Lincoln Crowley QC
- Janice Crawford
- Andrew Fraser
- Simone Fraser
- Ben Power
- Georgina Wright.

On 3 August 2020, the Attorney-General appointed three additional Counsel to assist the Royal Commission:

- Dr Hayley Bennett
- Elizabeth Bennett
- Melinda Zerner.

We acknowledge the support of Michael Fordham SC, Christine Ronalds AO SC, Malcolm Harding SC, Rebecca Treston QC and Sarah McCarthy, who assisted the Royal Commission during its establishment phase.

Support and wellbeing

The Royal Commission supports flexible working arrangements for staff. This includes providing technology that allows people to work away from the office. These arrangements allowed staff to adapt quickly to working from home when COVID-19 restrictions came into force in March 2020.

We offer pre-start meetings to new staff to discuss any adjustments needed and to allow them to familiarise themselves with the floor/work space.

Personal Emergency Evacuation Plans are prepared for staff who may need help vacating the building in an emergency.

We provide assistive technologies for staff who need them. These include screen readers, braille printers, portable hearing loops, voice recognition software, and hardware and software adjustments for staff with visual needs. We have a full-time in-house Director of Interpreting who, along with a team of external interpreters, provides professional Auslan interpreting and translation services. These services ensure the Deaf community can engage with the Royal Commission through, for example, our public hearings and community forums.

All staff receive disability access and awareness training. The training addresses the history of the disability sector, disability rights, the importance of trauma-informed practice, managing vicarious trauma, cultural awareness, and accessible and inclusive communication.

Commissioners and staff can be exposed to confronting information and accounts of traumatic personal experiences. We recognise the risk of vicarious trauma and have put measures in place to care for their health and wellbeing. All staff can choose to participate in quarterly wellbeing checks conducted by external psychologists. These checks not only enable staff to maintain wellbeing but equip them to better manage stressful situations. Commissioners can use the wellbeing checks or make their own arrangements. Staff and their families also have access to an Employee Assistance Program that provides confidential counselling.

Our premises

Offices

The Royal Commission has offices in Brisbane, Sydney and Canberra. We engaged a disability access consultant to help make them inclusive and accessible. The fit-outs of the Brisbane and Sydney offices were based on leading accessibility design principles (called universal design) and technology. For example, doors open and close remotely, surface contrasts help navigate the space and work stations incorporate adjustable designs.

Locations for public hearings and events

Accessibility is the main priority when deciding where we will hold a public hearing or event. It is often challenging to find venues that meet accessibility criteria, particularly outside capital cities. Staff visit potential sites and assess them using a comprehensive checklist, which includes:

- transport
- a continuous accessible path to entrances and while in the venue
- the internal layout of public areas
- bathroom facilities
- door measurements
- accessible evacuation plans
- signs in braille.

Our Brisbane office has a purpose-built public hearing room that has been designed and fitted-out using universal design principles. The features of the hearing room include:

- the ability to move chairs in the public gallery to allow any person to sit in any place they choose
- fully adjustable bar tables to provide Counsel Assisting with greater accessibility
- a dedicated and carefully configured space for Auslan interpreters to work during hearings.

For more information on the steps taken to ensure public hearings are accessible and tailored to the needs of particular witnesses, see Chapter 6.

Our finances

The Australian Government has provided $527.9 million over five years from 2018–19 to support the work of the Royal Commission.[5] This is made up of:

- $310.9 million over five years to the Royal Commission to undertake its operations
- $68.2 million over five years to the Attorney-General's Department to provide legal assistance to witnesses and to represent the Commonwealth in Royal Commission proceedings
- $148.8 million over three years to the Department of Social Services, the National Disability Insurance Agency and the NDIS Quality and Safeguards Commission to provide counselling services and other support to people with disability in connection with their participation in the Royal Commission.

The Royal Commission has spent $58.696 million from its budget.

Endnotes

[1] *United Nations Declaration on the Rights of Indigenous Peoples*, GA Res 61/295, UN GAOR, 61st Sess, 107th plenary mtg, Agenda Item 68, Supp No 49, UN Doc A/Res/61/295, Annex, (2 October 2007) 295.

[2] 'Accessibility and Inclusion Strategy', *Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability*. <https://disability.royalcommission.gov.au/publications/accessibility-and-inclusion-strategy>

[3] 'Affirmative measure for recruiting people with disability: A guide for agencies', *Australian Public Service Commission*, guidance material, 29 May 2018. <www.apsc.gov.au/affirmative-measure-recruiting-people-disability-guide-agencies>

[4] *Australian Public Service Commissioner's Directions 2016* (Cth) s 27.

[5] Funding is described as being provided for a full year irrespective of the period within the year to which the funding applies. For example, 2018-19 funding applies only to the period April 2019 (start of the Commission) to 30 June 2019.

Toby and Gavin*

Toby’s dad, Gavin, made a submission in which he described Toby’s experiences in employment.

Toby, who has moderate intellectual disability, knows kitchens. He had been working in different kitchens for businesses large and small for 15 years when he started a job in a hotel early last decade. Toby wasn’t too bothered by the initial pranks and ‘tomfoolery’, until what Gavin calls ‘the bad stuff’ started.

What began as ‘jokes’ soon became unwelcome, prolonged, repetitive, intimidating and harassing. The attacks were mostly perpetrated by a particular chef, Chad, who was often left in charge. Gavin described just a few of these incidents.

One was where Chad and his mate locked Toby in the freezer, leaving him cold and scared and screaming to get out.

Another time they sprayed Toby’s shaved head with oil, then set his head and t-shirt alight.

Chad told Toby he had to pay him $10 for every day he was kept in the job. Sometimes Toby paid, Gavin said, and when he didn’t, Chad would remind him he was keeping a total of how much Toby owed.

Sometimes Chad and his mate would stand behind Toby, grabbing his buttocks and pushing their groin into his backside, shouting obscenities.

One time Chad and his mate took a large kitchen knife, made Toby close his eyes, and dragged the blunt side along his arm. Next time, they promised, they would ‘do it for real’.

Toby was frightened and humiliated and it was beginning to interfere with his work performance.

He didn’t want his parents to know what was going on at work, but he did confide in his disability support workers. After the freezer incident one of the support workers decided to tell Toby’s parents.

From that point, Gavin said Toby became extremely anxious and afraid to attend work. He asked his mum to call work and say he was unavailable for the upcoming shifts on which Chad would be overseeing the kitchen.

Gavin told us he rang the hotel and the catering company to let them know about the bullying and harassment and that Toby wouldn’t be returning. They met with the manager and the head chef, who just said he was sorry it had happened and that he had given Toby the job because he was a good worker. The manager promised there would be an investigation, and written warnings to Chad and his mate, but Toby’s parents never saw written proof of the investigation.

Gavin told us they asked Toby whether anyone else saw or heard any of the attacks. Toby said that other workers did see things and he thought someone would tell Chad and his mate to stop. But no one did.

They also asked Toby why he didn't tell them that things were so bad. His response was, 'I only wanted to work'.

Following these events, Toby made a claim to the work, health and safety regulator regarding his stress and inability to work. He did receive compensation, but there was no response at all from the company.

Gavin told us:

> the catering industry is rife with abuse of persons with a disability … my son was advised never to work in this industry again because of abuse in various businesses.

He said he has spoken about this abuse with employee groups that assist people with disability in the employment field:

> I got the impression that it was not a good thing to make waves as it could impact others looking for employment and put in jeopardy the government subsidy of employing people with a disability and therefore employment services for people with a disability would lose their subsidies from the government.

Gavin says he's been left feeling that employment services assisting people with a disability are 'more concerned for the business than they were for the client's wellbeing and exploitation'.

*** Names changed and some details removed to protect people's identities. Narrative based on a submission to the Royal Commission.**

Part B: How we do our work

Part B of the interim report outlines how the Royal Commission does its work, through public hearings, submissions, community engagement, private sessions and our research and policy work. It also describes the support available to people who engage with the Royal Commission.

Chapter 6, ‘Support for people engaging with the Royal Commission’ describes the trauma-informed approach we take to all aspects of our inquiry, and the support available to people who engage with the Royal Commission.

Chapter 7, ‘Public hearings’ describes the formal proceedings through which witnesses give evidence about events and issues relevant to the Royal Commission’s terms of reference. It describes how public hearings enable people with disability and their families and supporters to share experiences of violence, abuse, neglect and exploitation. Experts, advocacy groups, academics and government agencies may also give evidence.

Chapter 8, ‘Submissions’ outlines how individuals and organisations are able to share their experiences, insights and proposals for change with the Royal Commission. The chapter explains that submissions can be about any issues that fall within our terms of reference and can be made in a variety of ways, including in writing, over the telephone, as videos or even as artwork.

Chapter 9, ‘Community engagement’ sets out the principles that govern how we engage with people with disability and the wider community. It also describes our approach to targeted engagement with First Nations communities, culturally and linguistically diverse people with disability, people with cognitive disability and people with disability who live or work in closed environments.

Chapter 10, ‘Private sessions’ describes how individuals can confidentially share their experiences with a Commissioner in a safe, supportive and accessible environment. The chapter outlines how private sessions help the Royal Commission to better understand the impacts of violence against, and abuse, neglect and exploitation of, people with disability, and to explore ideas as to how these experiences can be prevented.

Chapter 11, ‘Research and policy’ provides an overview of our research agenda, which investigates (among other topics) the history, nature and extent of violence, abuse, neglect and exploitation experienced by people with disability. The chapter also outlines our policy work, which is directed at the systemic factors that contribute to violence against, and abuse, neglect and exploitation of, people with disability and the development of recommendations that will lead to lasting change.

Content warnings

Please be aware that this report contains information that may be distressing to readers.

It includes accounts of violence against, and abuse, neglect and exploitation of, people with disability and references to suicide and self-harming behaviours.

In some first-hand accounts of violence, abuse, neglect and exploitation, people have told us of abusive or offensive language they have experienced or witnessed. As a result, some direct quotes in the report contain language that may be offensive to some people.

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

If you need support to deal with difficult feelings after reading this report, there are free services available to help you. Information about these services can be found at the beginning of this report (see page vi) and in Chapter 6.

6. Support for people engaging with the Royal Commission

Key points

- The Royal Commission commits to taking a trauma-informed approach to all aspects of our work.
- This means that we must understand the physical, social and emotional impacts of violence and other forms of trauma and integrate this understanding into our work. We aim to minimise re-traumatisation and to encourage people to feel physically, emotionally and culturally safe when engaging with us.
- We have a team of counsellors available to provide support to people, however they choose to engage with us.
- Where possible, we link people with a staff member of their preference and aim to have the same staff member available to them throughout their contact with the Royal Commission.
- The Royal Commission can also refer people to a range of external services, including those funded specifically by the Australian Government.

Introduction

This chapter outlines what it means for the Royal Commission to take a trauma-informed approach to all aspects of our work.

It provides information on and examples of how we embed this approach within the Royal Commission to support people to engage with us – from their first contact with the Royal Commission, throughout the engagement process, and afterwards, if required.

It also outlines the government-funded services offered to people with disability and their families and support people who engage with or are affected by the Royal Commission.

Our commitment to a trauma-informed approach

> Counsel Assisting and the Commission recognise that when engaging with the Commission people may be reliving traumatic experiences, and that these experiences can have ongoing impacts. To address this the Commission will adopt a trauma-informed approach when engaging with the community, having regard to the key principles of safety, transparency, empowerment, capacity to collaborate and cultural safety.[1]
>
> Senior Counsel Rebecca Treston QC

What is trauma?

Many people who have shared or will share their experiences of violence, abuse, neglect and exploitation with the Royal Commission have either personally lived through or have witnessed traumatic events. The United States Substance Abuse and Mental Health Services Administration's definition of trauma highlights the extent to which it can affect an individual's life:

> Individual trauma results from an event, series of events, or set of circumstances that is experienced by an individual as physically or emotionally harmful or life threatening and that has lasting adverse effects on the individual's functioning and mental, physical, social, emotional, or spiritual well-being. [2]

An experience of trauma is less about the event itself and more about how it is experienced by the person.[3] Events and circumstances may include an actual or perceived threat of physical or psychological harm (for example, natural disasters, violence and abuse, and so forth)[4] and typically involve the loss of control, betrayal, abuse of power, helplessness, confusion and/or loss. These events and circumstances may occur once, multiple times or repeatedly over time.[5]

The term 'intergenerational trauma' refers to the way in which trauma experienced by one generation affects the health and wellbeing of their descendants.[6] It is often used to describe the trauma of events associated with the colonisation of First Nations people and lands such as the impacts felt by members of the Stolen Generations.[7] Intergenerational trauma may also be used to describe the impact of the traumatic experiences of refugees and asylum seekers on their families and communities.[8]

What is a trauma-informed approach?

The Royal Commission is committed to adopting a trauma-informed approach to all aspects of our work. A trauma-informed approach requires an organisation to ensure its staff understand the impacts of trauma[9] and put in place strategies that minimise, as far as possible, the risk that people may be re-traumatised.[10]

The Royal Commission aims to safeguard and promote the physical, social, emotional and cultural safety of everyone who engages with us. We do this by seeking to ensure that everyone within the organisation, including Commissioners, Counsel Assisting and senior staff:

- understands the physical, social, cultural and emotional impacts of violence, abuse, neglect and exploitation on people with disability and others engaging with the Royal Commission
- integrates that understanding into all aspects of the work of the Royal Commission, including public hearings and all forms of engagement
- develops and implements processes and practices that minimise the risks of re-traumatisation.[11]

We want people with disability, their families and supporters to feel comfortable to share their experiences with us. We aim to create an environment where they will be safe and supported to do so.

Vicarious trauma

Vicarious trauma 'occurs as a result of chronic secondary exposure to traumatic material'.[12] Embedding a trauma-informed approach requires the Royal Commission to acknowledge the potential for Commissioners, Counsel Assisting and staff to experience vicarious trauma, and the need for self-care and organisational care.[13] We talk about supports provided for Commissioners and staff in Chapter 5, 'Our organisation'.

How we support people who engage with us

Our Intake, Counselling and Support team

To help us apply a trauma-informed approach to our work, we have engaged experienced counsellors as part of our Intake, Counselling and Support team.

Team members are qualified social workers and counsellors, with extensive experience working with people with disability and with people who have experienced complex trauma. Their role includes:

- assisting people contacting our enquiries phone line who may require additional support to share their experiences, or who may be distressed
- assisting people to make submissions, including by taking submissions over the phone
- working with teams across the Royal Commission to provide support to people participating in engagement activities, such as community forums or targeted engagements (see Chapter 9, 'Community engagement'), public hearings (see Chapter 7, 'Public hearings') and private sessions (see Chapter 10, 'Private sessions'). This support is available before, during and after the individual's engagement with us
- discussing support, reporting options and safety concerns with people sharing their experiences via submissions or other engagement activities
- providing advice and support to other teams across the Royal Commission to help them carry out their work consistent with a trauma-informed approach.

The team also reviews the Royal Commission's policies and procedures to ensure all aspects of our inquiry are appropriately trauma-informed.

The team is gender and age diverse, and includes First Nations people, people from culturally and linguistically diverse backgrounds and people with disability.

Where we can, we link people engaging with the Royal Commission with a staff member of their preference. We aim to have the same counsellor support people throughout their contact with the Royal Commission. This enables consistency of support and minimises people having to repeat their experiences or accessibility requirements.

Support from first contact

A priority for the Royal Commission is that anyone, and especially people with disability, can easily engage with us, to access information about our work and to share their experiences with us.

Our first points of contact are our email inbox and our enquiries phone line (1800 517 199), which operates Monday to Friday between 9 am and 5 pm Australian Eastern Standard Time (AEST), except on national public holidays.

Since commencing its operations, as of 31 July 2020 the Royal Commission's intake function has received 6815 enquiries via phone and email.

We aim to ensure that everyone receives a first response within 48 hours. Applying a trauma-informed approach, our intake officers answer queries and explain how people can share their experiences with the Royal Commission.

Common issues people contact us about include:

- making a submission
- support services
- public hearings
- community forums
- private sessions
- the purpose of the Royal Commission and our terms of reference.

Counsellors may refer people contacting the Royal Commission who require ongoing support to Blue Knot Foundation, an external national counselling and referral service, or to other face-to-face counselling services across Australia. With consent, we can connect people to other government-funded supports or assistance and provide information about existing complaints mechanisms relevant to their enquiry. (See 'Support available from external services' later in the chapter for more information about external support services.)

The Translation and Interpreting Service[14] is available to help people communicate with us in their preferred language. The National Relay Service[15] supports people who are deaf, hard of hearing and/or have a speech impairment to make and receive phone calls. These resources can be accessed by anyone communicating with us who needs them.

Support from the first phone call

Rose* contacted our enquiries phone line and reported being in significant distress. Rose was experiencing homelessness and told us she had an acquired brain injury and mental health issues.

Rose had been through significant trauma over her lifetime, which she told us included abuse while in a residential facility. After a lengthy conversation with a counsellor she agreed to a safety plan that involved regular follow up contacts by the staff member.

Speaking with Rose several times, Royal Commission staff linked her with appropriate support services. After several weeks, she felt safe enough to share her experiences with us through a phone submission. The phone submission was taken over several days and the information provided was read back to Rose for confirmation before being submitted.

Rose has now told us she is using independent support services and her informal supports to move out of her crisis situation.

Rose has contacted the enquiries phone line on several occasions to update the Royal Commission on her progress and express her thanks for the support provided.

*** Name changed and some details removed to protect people's identities.**

Support at community forums

Counsellors are present at all Royal Commission community forums and are available to offer support to anyone who attends. This can include people who share their experiences at the forum, as well as community members who may be impacted by the information shared.

During a forum, counsellors:

- provide information about the work of the Royal Commission
- provide referrals to external services if required
- offer a quiet space away from the event for anyone who needs it
- offer support to people who may become distressed.

Anyone who engages with a counsellor at a community forum and would like follow up support is contacted afterwards and may be offered referrals to external services.

Occasionally, people attending community forums may share information about abuse, violence, neglect or exploitation they are currently experiencing. The Royal Commission has a number of procedures in place to manage these disclosures. The role of counsellors is to be available to offer brief counselling, support and assistance with safety planning and referrals to local services if ongoing support is required.

When organising venues for community forums, the Royal Commission books an additional 'break out' room for use by the counselling team. Counsellors speak with people in this private setting to ensure confidentiality.

People at community forums have expressed to counsellors concerns about immediate risks of family and domestic violence, lack of appropriate support services and threats of self-harm or harm to others. Counsellors have helped people connect with emergency services, assisted with safety planning and facilitated referrals to local agencies for ongoing support. In the week following a community forum, counsellors follow up with people they had contact with to ensure they are receiving appropriate support.

See Chapter 9 for more information on community forums.

Support at community forums leads to further engagement

Before the start of one of the Royal Commission's community forums, counselling staff were made aware of Korbin*, who seemed unsettled and anxious.

A member of our First Nations counselling team approached Korbin to welcome him and to find out if there was anything we could do to make him feel comfortable and supported to participate.

Following support from the counsellor, Korbin joined the forum, to listen and observe. The counsellor spent time with Korbin after the forum to talk about the different ways people can engage and share their experiences with the Royal Commission. Korbin was interested in further engagement. He indicated that a private session would suit him best and that he would like to be able to keep working with First Nations staff.

The First Nations counsellor ensured Korbin was supported to register for a private session and that his preference to work with First Nations staff in the private sessions team was known and understood. The First Nations counsellor also worked with Korbin to explore other local supports he could access.

*** Name changed and some details removed to protect people's identities.**

Support at public hearings

Royal Commission counsellors attend all public hearings and are available to provide support to anyone attending. Counsellors also work with the Office of the Solicitor Assisting(OSA) to offer potential witnesses assistance before, during and after public hearings.

Before a public hearing

Before a public hearing, counsellors are available to:

- offer support to potential witnesses
- work with OSA to arrange witness familiarisation sessions
- assist witnesses in preparing for being a witness, and to relay information about the hearing process
- attend interviews with witnesses and provide support while witnesses are preparing statements and afterwards
- make referrals to external support services.

Support for a potential witness from First Nations counselling staff

On reading Betty's* submission to the Royal Commission, the Office of Solicitor Assisting (OSA) considered she may be a suitable witness for a scheduled hearing.

Betty had identified herself as a First Nations woman and, on contacting her, the Royal Commission made her aware that First Nations counselling staff were available to participate in any meetings and communication should she welcome that support.

Betty accepted this offer, noting that it helped having someone who shared her culture and 'who understood'.

Betty lives in a regional community. Royal Commission staff offered to travel to her area to take her witness statement and to provide the appropriate cultural and emotional support. Staff made two trips, meeting Betty at the location she identified as being safest for her.

The same First Nations counsellor was able to continue to support Betty through to her attendance at the scheduled hearing. Since the hearing, the counsellor has contacted Betty several times to check in with her and discuss possible ongoing support options.

*** Name changed and some details removed to protect people's identities.**

Providing physical and emotional safety

Priya* made a submission to the Royal Commission about her child Andy's experiences at school. Priya had indicated a willingness to be contacted and was approached by the Royal Commission as to Priya and Andy being potential witnesses for a scheduled hearing. Priya and Andy live in a regional centre, and have a range of accessibility and sensory needs that the Royal Commission needed to understand to ensure Priya and Andy felt physically and emotionally safe to participate.

A counsellor and an OSA staff member worked with them on where they would feel most comfortable to meet. They nominated a local advocacy centre that they had positive experiences with.

Royal Commission staff liaised with staff at the centre to arrange a suitable room. Adjustments were made to the physical environment to meet accessibility and sensory needs, including to accommodate a support animal. Enough time was allocated to ensure the Royal Commission understood Priya and Andy's needs, and to assure them that we would be guided by them in terms of the pace of the meeting and when breaks should occur.

The hearing has been postponed due to COVID-19 restrictions. Our counsellor remains in regular contact with Priya and Andy to provide them with updates and continue preparing for the hearing.

*** Names changed and some details removed to protect people's identities.**

During a public hearing

During a public hearing, our counsellors can:

- with other staff, ensure witnesses are prepared and ready to give evidence when called
- provide support and debriefing to witnesses and their supporters
- provide information and support to the public attending the hearing
- make referrals to external services where required.

After a public hearing

After a public hearing, the Counselling and Support team makes contact with witnesses. This is to:

- ensure their wellbeing and safety have not been compromised
- offer a debrief and reflection on their experience of the public hearing
- ensure they have sufficient support in place and are aware of alternative providers, including the Blue Knot Foundation
- make referrals to external services where required.

Our approach in practice – Public hearing 4: Health care and services for people with cognitive disability

> Giving evidence at the Royal Commission felt like getting my power back.[16]

Over two weeks in February 2020, the Royal Commission held a public hearing to examine health care and services for people with cognitive disability, including people with intellectual disability, autism and acquired brain injury.

Witnesses supported during the hearing process included people with disability and their family members. Royal Commission staff collaborated with these witnesses and their support people or advocates, to ensure that we understood each of their preferences and needs. We particularly acknowledge the assistance of Mr Jim Simpson and other staff from the NSW Council for Intellectual Disability for their advice and assistance.

This collaboration resulted in redesign of the hearing room to create an environment in which witnesses with a disability said they felt safe to give their evidence. Changes made included removing the raised platform where Commissioners would normally sit, and seating witnesses with their backs to the gallery to minimise distractions.

Familiarisation day ahead of hearing

Before the hearing, a ‘practice day’ was set aside for witnesses with disability and their families and supporters. This was an opportunity to meet with Counsel Assisting and some Commissioners, and to ‘step through’ the process for the public hearing and become familiar with the venue.

Our counsellors worked together with staff from the Office of the Solicitor Assisting to help witnesses identify their needs for the day of the hearing, such as their travel arrangements, their support people and what would help make them feel safe and ready to participate. Some witnesses chose to be supported by family and friends and requested minimal support from Royal Commission counselling staff. Others chose to be supported by a Royal Commission counsellor on the day and not involve friends or family.

Counsellors worked with witnesses to prepare for the emotions the day could likely bring and what could be done to minimise and manage any distress.

The hearing venue included break out spaces for witnesses, and others attending impacted by the material or proceedings, to take a break if needed. On the day, counselling staff helped witnesses to access these break out spaces. Witnesses were also kept informed of the process of the hearing and any changes to it, and supported to think through whether they would like to accept requests from media.

After the hearing, witnesses were offered follow up contact, through their preferred method of contact. This was to ensure their wellbeing and safety had not been compromised, and to offer a further debrief and opportunity to discuss any ongoing support needs.

All witnesses were made aware of ongoing supports available to them and offered assistance in accessing these services. Some people accepted this offer, while others chose not to at that time. Referrals to ongoing support are only ever made with the individual's consent.

The Royal Commission was pleased to receive feedback that because of the support offered, people felt empowered to share their experiences.

See Chapter 7 for more information about public hearings.

Support at private sessions

Some people share their experiences of violence, abuse, neglect or exploitation with a Commissioner in a confidential meeting, called a private session.

Before the session, a counsellor contacts the person who is to attend. The same counsellor can provide support leading up to, during and following the private session.

Support that counsellors provide for private sessions includes:

- checking in regularly with those involved about their needs on the day
- greeting people on their arrival
- explaining the process for the private session and helping those attending to feel safe and ready to participate
- offering to debrief those attending immediately after the private session to ensure they are feeling comfortable and safe to leave
- following up with people to provide an opportunity for further debriefing and for feedback about their experience of the private session
- connecting people with ongoing support if required.

See Chapter 10 for more information about private sessions.

Support for people accessing private sessions

Jordan* accessed support from the counselling team in her early engagement with the Royal Commission and before registering for a private session. The same counsellor supported her before, during and after her private session. This limited the number of people Jordan had to share her story with and allowed for a better understanding of her needs.

Jordan was sharing an experience of a loved one who was unable to directly participate in the session. Jordan and the counsellor discussed what Jordan wanted to do to bring her loved one 'into the room'. Jordan decided to share video footage of her loved one with the Commissioner and private sessions staff. She said this was important, so everyone in the room knew they were 'talking about a person', a 'human being who is loved'.

The counsellor checked in with Jordan the week after her private session to provide an opportunity to reflect on the experience, give feedback and to discuss any ongoing support needs. Jordan said it had been an emotionally difficult experience that she was still processing. However, she said she was glad she had been able to share her experience and views directly with a Commissioner.

*** Name changed and some details removed to protect people's identities**

Support available from external services

In addition to the support the Royal Commission provides, people who engage with or are impacted by our inquiry can access free support from a number of other services. These include:

- national telephone counselling and referral
- advocacy
- face-to-face support
- legal advice.

National telephone counselling and referral service

Blue Knot Foundation

As noted earlier, an independent national telephone counselling and referral service is available to people engaging with or affected by the Royal Commission. It is provided by the Blue Knot Foundation[17] and is funded by the Australian Government Department of Social Services.

Blue Knot offers specialist trauma-informed counselling for anyone affected by the Royal Commission, including people with disability, their families and support people. People can connect by:

- phone
- video conference
- webchat
- SMS.

Blue Knot operates a national phone line (1800 421 468) between 9 am and 6 pm Monday to Friday (AEST), and 9 am to 5 pm (AEST) on weekends and public holidays. Blue Knot staff can use the National Relay Service or the Translation and Interpreting Service (TIS) to take calls if needed.

State and territory support service providers

Support services in all states and territories[18] have been funded by the Australian Government Department of Social Services to provide counselling support[19] to people who are affected by the Royal Commission. Services include:

- counselling (face-to-face, online and over the phone)
- access to an interpreter or cultural translation services
- supported referrals to appropriate specialised services
- information about and referrals to other useful services.

Free counselling support services listed by state and territory

Australian Capital Territory

- Relationships Australia Canberra and Region

New South Wales

- Relationships Australia New South Wales
- Interrelate Limited

Northern Territory

- Relationships Australia Northern Territory
- Danila Dilba Biluru Butji Binnilutlum Health Service Aboriginal Corporation Northern Territory

Queensland

- Micah Projects
- Cape York/Gulf Remote Area Aboriginal and Torres Strait Islander Child Care Advisory Association Inc.
- WWILD

South Australia

- Relationships Australia South Australia
- Nunkuwarrin Yunti of South Australia

Tasmania

- Relationships Australia Tasmania

Victoria

- Relationships Australia Victoria
- Drummond Street Services

Western Australia

- Relationships Australia Western Australia
- Kimberley Stolen Generation Aboriginal Corporation Western Australia
- Yorgum Healing Services Aboriginal Corporation Western Australia.

Advocacy support services

The Australian Government Department of Social Services has extended the National Disability Advocacy Program (NDAP)[20] to include individual advocacy for people who need extra support to engage with the Royal Commission.

Advocacy support is available to people with disability (or family members or support people acting on their behalf) who may have difficulty in communicating, or understanding how to engage, with the Royal Commission. Those who advocacy support is available to includes First Nations people, culturally and linguistically diverse communities, LGBTIQ+ people, people with intellectual and cognitive disability, young people with disability, and women and girls with disability.

Free advocacy support services listed by state and territory

Australian Capital Territory

- ACT Disability, Aged and Carer Advocacy Service (ADACAS)
- Advocacy for Inclusion

New South Wales

- Disability Advocacy NSW
- Illawarra Advocacy
- Intellectual Disability Rights Service
- Multicultural Disability Advocacy Association of NSW (MDAA)
- Newell Advocacy

- SCIA Advocacy Northern Rivers
- Self Advocacy (Sydney)
- Regional Disability Advocacy Service (RDAS)
- Side By Side Advocacy
- Sydney Region Aboriginal Corporation
- Family Advocacy
- People with Disability Australia (PWDA)

Northern Territory

- Darwin Community Legal Service
- Disability Advocacy Service Inc (DAS)
- Ngaanyatjarra Pitjantjatjara Yankunytjatjara Women's Council (NPY Women's Council)

Queensland

- Aged and Disability Advocacy Australia (ADA Australia)
- Independent Advocacy in North Queensland
- Disability Rights Advocacy Service
- Mackay Advocacy
- People with Disability Australia (PWDA)
- Queensland Advocacy
- Rights In Action
- Speaking Up For You (SUFY)
- TASC National

South Australia

- Advocacy for Disability Access and Inclusion
- Disability Advocacy and Complaints Service of South Australia (DACSSA)
- Disability Rights Advocacy Service
- Independent Advocacy SA

Tasmania

- Advocacy Tasmania
- Speak Out Association of Tasmania (Speak Out)

Victoria

- Action for More Independence & Dignity in Accommodation (AMIDA)
- Action on Disability within Ethnic Communities (ADEC)
- Association of Employees with Disability
- Colac Otway Region Advocacy Service (CORAS)
- Disability Justice Australia
- Gippsland Disability Advocacy (GDA)
- Grampians disAbility Advocacy Association
- Leadership Plus
- Melbourne East Disability Advocacy (MEDA)
- North East Citizen Advocacy
- Rights Information and Advocacy Centre (RIAC)
- Southern Disability Advocacy

- Southwest Advocacy Association (SWAA)
- Victorian Mental Illness Awareness Council (VMIAC)
- Villamanta Disability Rights Legal Service
- Regional Disability Advocacy Service (RDAS)

Western Australia

- Advocacy WA
- Ethnic Disability Advocacy Centre
- Midland Information, Debt & Legal Advocacy Service (MIDLAS)
- People With Disabilities WA (PWDWA)
- Sussex Street Community Law Service.

Legal advisory service

The Australian Government Attorney-General's Department has funded National Legal Aid and the National Aboriginal and Torres Strait Islander Legal Service to establish Your Story Disability Legal Support to provide free legal advice to anyone engaging with the Royal Commission. This includes offering free legal advice to Aboriginal and Torres Strait Islander people within a community-controlled setting.

The service can be accessed online at Your Story Disability Legal Support.[21] The service operates a phone hotline between 9 am and 5 pm (AEST), Monday to Friday.

Legal financial assistance

The Australian Government Attorney-General's Department may be able to help in some instances with the costs of legal representation[22] and some of the costs of engaging formally with the Royal Commission, for example resulting from:

- being called, or granted leave to appear, as a witness at a hearing of the Royal Commission
- being requested to attend, or attending, an interview with the Royal Commission
- complying with a notice to give information or a statement in writing that will be used as evidence in the Royal Commission
- complying with a notice to produce issued by the Royal Commission.

If a person has been called by the Royal Commission in their personal capacity, they may be eligible for legal financial assistance.[23] They may also be eligible if their organisation has been called, subject to an assessment of whether the organisation can meet the cost of legal representation without incurring serious financial difficulty.

The Attorney-General's Department website includes information[24] on the legal financial assistance scheme, including eligibility and how people can apply.

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Mary*

Mary is a young woman with disability, with no living family. She experiences chronic pain and is a wheelchair user. In her submission, Mary told us her disability support provider has abused and exploited her over many years. 'Years of being fobbed off. Playing with my life,' Mary said of her provider.

Mary said the support provider lied to her, telling her that her state funding covered a maximum of two hours of domestic assistance a week, which didn't include food preparation. Mary only recently learned that this was incorrect and she was always supposed to have the choice – domestic support, social support, respite or a combination of different types of support.

Instead, without consulting her, the provider decided Mary would have two hours of domestic support and three hours of social support. 'I never wanted social support,' Mary said. 'I was told this had to be this way.'

Every support worker, year after year, refused to provide domestic help, which was what she really needed. 'They don't clean ... they all demand tea and coffee that I have to provide and pay them to drink,' said Mary, because 'they are here to do social support not work.'

'One kept yelling,' Mary remembers, 'leaning into my face, dragging out her words and drawing pictures in the air ... I'm not intellectually disabled.'

Mary said the workers would always move things in her home, despite her explaining that she needed things in certain places so she could reach them. But the workers would treat it like a joke. Mary told the provider many times that they need to train their staff in disability, but the response was that training is a waste of time – that these things are 'common sense'.

Meanwhile, Mary was 'going in and out of counselling, many break downs, and physical health deterioration fighting for more domestic help, food preparation help ... all those tears and stress and 2 attempts to take my life'.

Mary complained many times about the service. And each time she had a health problem she would beg for more help. They would have a meeting in which Mary was 'loud and clear' about her needs, but the staff never acted on the new care plans. One day she saw her file open on the provider's computer and found out no care plan had ever been recorded.

'How many others are in my situation?' Mary asks.

*** Name changed and some details removed to protect people's identities. Narrative based on a submission to the Royal Commission.**

7. Public hearings

Key points

- Public hearings play a significant role in the work of the Royal Commission.
- Public hearings enable:
  - the Royal Commission to hear evidence from a range of sources about matters within its terms of reference and to explore issues in detail
  - the Royal Commission and the general public to hear from people with disability about their individual experiences of violence, abuse, neglect and/or exploitation
  - witnesses, including people with disability, their families and supporters, to share their experiences with the Royal Commission in a public forum. For many, this will be the first time they have been given a voice.
- As at 31 July 2020, the Royal Commission had held four public hearings. These were the ceremonial opening sitting, and hearings focusing on inclusive education in Queensland, the experiences of people with disability living in a group home, and health care and services for people with cognitive disability.
- The Royal Commission suspended public hearings from March 2020 until August 2020 due to the COVID-19 pandemic.
- In July 2020, the Royal Commission announced further planned public hearings for the remainder of 2020, subject to any significant changes in circumstances.

Introduction

One of the principal features of royal commissions is the public nature of their inquiries, most commonly expressed in the form of public hearings.[1]

Public hearings conducted by royal commissions are formal proceedings in which witnesses give evidence, under oath or affirmation, about events and issues that are relevant to the terms of reference.

For this Royal Commission, the importance of providing a public forum for people with disability, their families and supporters to share their experiences of violence, abuse, neglect and exploitation cannot be overestimated.

This chapter outlines:

- the purpose of public hearings
- the approach this Royal Commission takes to public hearings, including:
    - our hearing program and how we decide what to focus on
    - the role and nature of witnesses who give evidence at public hearings.

Purpose of public hearings

Public hearings are a critical part of this Royal Commission's work. They serve a range of purposes, enabling the Royal Commission to:

- obtain information that exposes the nature and extent of violence, abuse, neglect and exploitation experienced by people with disability, as well as the measures required to prevent violence, abuse, neglect and exploitation
- hear and test evidence from witnesses, including people with disability, their family members, support people, service providers, advocates and experts
- where appropriate, make findings of fact based on that evidence, whether relating to allegations against specific individuals or entities, or on more general issues such as deficiencies in policies or practices
- develop recommendations to government on matters within the terms of reference.

Public hearings also:

- provide people with relevant knowledge or experience with the opportunity to publicly share it with the Royal Commission
- provide members of the public with the opportunity to hear first-hand from people with relevant experience and/or expertise.

Appearing as a witness at a public hearing is just one way that people can share their experiences with the Royal Commission. Other ways include through providing a submission, participating in a private session, or making a statement at a community forum (see Chapter 8, 'Submissions', Chapter 9, 'Community engagement' and Chapter 10, 'Private sessions').

Our approach to public hearings

The hearing program

The nature and breadth of the terms of reference of this Royal Commission require a hearing program that allows for the examination of a broad variety of issues over the life of the inquiry, with later hearings building upon earlier ones.

This approach means that the Royal Commission may not make findings of fact or reach conclusions about particular issues until:

- after the last hearing at which evidence is presented on the relevant topic
- interested people and organisations have had an opportunity to make submissions on all of the evidence relating to the issue or issues.

Taking into account the effect of the pandemic, the practical consequence of this approach is that the Royal Commission will not make detailed or wide-ranging recommendations until later in the inquiry. This does not necessarily preclude the Royal Commission from making recommendations prior to the presentation of the final report.

The approach we are taking to hearings is different to that taken in other recent royal commissions, where hearings have, for example, been self-contained and often confined to specific issues and circumstances.

We consider a range of factors when deciding the subject matter of a particular hearing, including:

- whether and how a particular issue fits within the Royal Commission's terms of reference and hearing program
- whether the proposed hearing provides a good opportunity to explore widespread or systemic issues that can be demonstrated through individual experiences
- the significance of the specific issue to people with disability, including as shown by information received by the Royal Commission through submissions and community engagement
- practical considerations, including the availability of witnesses and relevant documents.

Witnesses

People who give evidence at a public hearing are called witnesses. Part of the role of the Solicitors and Counsel Assisting the Royal Commission is to identify appropriate witnesses for a public hearing.

For this Royal Commission, in general terms, witnesses can include:

- people with disability, their family members and supporters
- experts, including researchers or people with special knowledge or experience

- representatives from advocacy organisations
- representatives from disability service providers
- representatives from government departments and agencies.

An individual witness may of course fall into more than one category.

The Royal Commission applies a trauma-informed approach when engaging with all members of the public, and in particular with people with disability, who may have experienced trauma. For public hearings, this is reflected in the efforts of Royal Commission staff to create a safe and respectful environment where witnesses feel supported and empowered.

Full details of the Royal Commission's trauma-informed approach to its work are provided in Chapter 6, 'Support for people engaging with the Royal Commission'.

The Royal Commission has consulted with expert bodies and organisations to ensure as far as possible that witnesses, in particular people with disability, are able to give evidence in a way that best suits them and with which they are most comfortable.[2]

Examples of how evidence has been given include:

- by video link[3]
- using communication devices[4]
- incorporating videos[5]
- using photographs and other images[6]
- with Easy Read formatting of statements[7]
- with support persons.[8]

We have also trialled a practice session ahead of a public hearing so witnesses could become familiar with the hearing room and the process.

The Royal Commission also seeks to ensure that witnesses are supported not only before and while, but after they give evidence.

More information about this support is outlined in Chapter 6.

Accessing public hearings

Public hearings are, by their very nature, open to the public. All public hearings of this Royal Commission have real time closed captioning and Auslan-English interpreters, and proceedings are live streamed. The videos and transcripts are available on our website.[9]

During the COVID-19 pandemic, government imposed restrictions may prevent members of the public from attending hearings in person. However, it will still be open to any member of the community to follow the proceedings on the live stream.

Further information on the measures the Royal Commission has taken to ensure our work, including public hearings, is inclusive and accessible is outlined in Chapter 5, 'Our organisation'.

Public hearings to date

As at 31 July 2020, the Royal Commission had held four public hearings, as set out in the table below.

Table 7.1 Royal Commission public hearings as at 31 July 2020

	Hearing	Date	Location	Commissioners
1	**Ceremonial opening sitting**	16 September 2019	Brisbane	All
2	**Inclusive education in Queensland – preliminary inquiry**	4–7 November 2019	Townsville	Hon Ronald Sackville AO QC Hon Roslyn Atkinson AO Dr Rhonda Galbally AC Ms Andrea Mason OAM
3	**The experience of living in a group home for people with disability**	2–6 December 2019	Melbourne	Hon Ronald Sackville AO QC Hon Roslyn Atkinson AO Mr Alastair McEwin AM
4	**Health care and services for people with cognitive disability**	18–28 February 2020	Sydney	Hon Ronald Sackville AO QC Hon Roslyn Atkinson AO Ms Barbara Bennett PSM Dr Rhonda Galbally AC

Summary reports of Public hearing 2, Public hearing 3 and Public hearing 4 appear in Chapters 12, 13 and 14, respectively.

Planned public hearings

In July 2020, the Royal Commission announced further planned public hearings for the remainder of 2020. Subject to any significant changes in circumstances, the Royal Commission will hold public hearings between August and December 2020 as set out in the table below.

Table 7.2 Royal Commission planned public hearings August–December 2020

	Hearing	Date	Location	Commissioners
5	**Experiences of people with disability during the ongoing COVID-19 Pandemic as at August 2020**	18–21 August 2020	Sydney	Hon Ronald Sackville AO QC Ms Barbara Bennett PSM Dr Rhonda Galbally AC
6	**Psychotropic medication, behaviour support and behaviours of concern**	Week of 21 September 2020	Sydney	Hon Ronald Sackville AO QC Hon Roslyn Atkinson AO Mr Alastair McEwin AM
7	**Barriers experienced by students with disability in accessing and obtaining a safe, quality and inclusive school education and consequent life course impacts**	Week of 12 October 2020	Brisbane	Hon Ronald Sackville AO QC Hon Roslyn Atkinson AO Dr Rhonda Galbally AC Ms Andrea Mason OAM

	Hearing	Date	Location	Commissioners
8	**The experiences of First Nations people with disability and their families in contact with child protection systems**	Week of 23 November 2020	Brisbane	Hon Ronald Sackville AO QC Hon Roslyn Atkinson AO Ms Andrea Mason OAM
9	**Systemic barriers in the pathways to employment for people with disability**	December 2020	Sydney	Commissioners to be confirmed
10	**Training and education of health care professionals in relation to people with cognitive disability**	December 2020	Sydney	Commissioners to be confirmed

Endnotes

1 Royal commissions have the power to conduct hearings in closed session in certain circumstances.

2 See also for example: Australian Guardianship and Administration Council, *Maximising the participation of the person in guardianship proceedings: Guidelines for Australian Tribunals*, Final report, June 2019.

3 Transcript, Rosemary Kayess, Public hearing 3, 6 December 2019, P-382–396.

4 Transcript, Peter Gibilisco, Public hearing 3, 2 December 2019, P-20–27; Transcript, Sam Petersen, Public hearing 3, 6 December 2019, P-434–440.

5 Transcript, Ruth Oslington, Public hearing 4, 18 February 2020, P-34 [34]; Exhibit 4-3, IND.0017.0001.0001, Transcript, Kylie Scott, Public hearing 4, 18 February 2020, P-23 [31]; Exhibit 4-1.1, NSW.9999.0002.0001, Transcript, Robert Strike AM, Public hearing 4, 28 February 2020, P-871 [1–11].

6 Transcript, Rachel Browne, Public hearing 4, 19 February 2020, P-68–69; Exhibit 4-5.1, IND.0011.0001.0003, Transcript, Rebecca Kelly, Public hearing 4, 18 February 2020, P-39 [6–12]; Exhibit 4-4.1, IND.0009.0001.0105, Transcript, Jayne Ann Lehmann, Public hearing 4, 26 February 2020, P-628–629; Exhibit 4-25.1, IND.0014.0001.0015, Transcript, Lorraine Clark, Public hearing 4, 21 February 2020, P-288 [15–29]; Exhibit 4-12.1, IND.0016.0001.0001, Transcript, Kim Creevey, Public hearing 4, 21 February 2020, P-315–316; Exhibit 4-13.1, IND.0010.0001.0001;Transcript, Jo Abi, Public hearing 4, 28 February 2020, P-825 [17–21].

7 Exhibit 4-1, ‘Statement of Kylie Scott’, 7 February 2020; Exhibit 4-14, ‘Statement of Tara Kate Elliffe’, 13 February 2020.

8 Transcript, Alan Robertson and Kevin Stone, Public hearing 3, 4 December 2019, P-155–170; Transcript, Jack Kelly and Justine O’Neill, Public hearing 4, 18 February 2020, P-25–34; Transcript, Robert Strike and Justine O’Neill, Public hearing 4, 28 February 2020, P-867–881.

9 ‘Public hearings’, *Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability*. <https://disability.royalcommission.gov.au/public-hearings>

Erin*

Erin is a disability support worker. She told us in her submission that when she started with her current organisation more than two years ago she witnessed mistreatment and abuse of clients by other staff members.

Erin said she used the organisation's complaints and incidents procedure to address the issues and, after some months – during which time the behaviours continued – the staff members who perpetrated the abuse were made redundant.

But the problem has not really been addressed, Erin said, and the two staff members in question are now working for another disability support service in the same town:

> I have great fears that these people may not have changed their behaviour. One of these staff members is now doing community access with a customer I support and they come to the residence where customers they previously mistreated live ... I have to be careful as I live in a small regional town where everyone knows each other, so I have been too scared to address this in any other way than to inform the Commission.

She noted that her customer, who goes on community access outings with one of these people, often returns in an agitated state: 'I am concerned what is being said and how she is treated whilst out with this staff member.'

Erin told us she thinks disability support organisations should check with previous employers if there have been complaints or incidents implicating a staff member they are considering for a job. She commented:

> We need people to not be scared of standing up for themselves and saying if they feel mistreated or for others to not be scared to speak up for those who cannot do so.
>
> ... I hope that all forms of abuse and violence towards anyone anywhere will be exposed and offenders made accountable and that our society moves towards being more fair and just.

*** Name changed and some details removed to protect people's identities. Narrative based on a submission to the Royal Commission.**

8. Submissions

Key points

- The submissions process is one of the key ways individuals and organisations provide the Royal Commission with information about their experiences of and insights into violence against, and abuse, neglect and exploitation of, people with disability.
- Submissions also:
  - help us understand systemic issues that people with disability and their families and supporters face
  - inform our investigations, research and policy work.
- All submissions we receive are read by Commissioners and relevant staff.
- Submissions can be made in a variety of formats – for example, in writing, over the phone, as videos or as artworks.
- Submissions can be about any issue that falls within our terms of reference.
- The Royal Commission will not make public any information provided in a submission without the consent of the submitter.
- The Royal Commission has to date received only a small number of submissions from some groups, such as First Nations, culturally and linguistically diverse, and LGBTIQ+ people with disability.
- We have similarly not heard from many people with disability who are residing in closed institutions such as prisons, detention centres, forensic disability and mental health institutions, and segregated living environments like group homes.

Introduction

One way the Royal Commission receives information from individuals, groups and organisations is through the submissions process.

This chapter explains what submissions are, how they can be made and why they are a critical part of our inquiry.

It also sets out:

- how people or organisations making submissions decide whether and how the Royal Commission may use their information, other than for internal purposes
- the steps the Royal Commission has taken to improve the submissions process.

The submissions described in this chapter are quite distinct from submissions made by parties who have been granted leave to appear at a particular hearing, or responses to issues papers. Submissions by a party at a public hearing usually relate to evidence that directly affects the interests of the party making the submission (see Chapter 7, ‘Public hearings’). Responses to issues papers are directed to a targeted area of interest for the Royal Commission (see Chapter 11, ‘Research and policy’).

What is a submission?

A submission is a statement to the Royal Commission from an individual, group of people, or an organisation about an issue within our terms of reference. It is one of the key ways of sharing experiences, insights and proposed recommendations with the Royal Commission.

A submission may deal directly (or indirectly) with violence against, and abuse, neglect or exploitation of, people or a person with disability. However, it may also identify other issues: for example, quality and safety of services; the role of families, support people and support staff; or best practice examples and proposed recommendations for supporting people with disability.

In addition to submissions from individuals sharing their experiences, the Royal Commission has received a number of submissions from researchers, disability advocacy organisations, government departments and agencies, and professional organisations.

Purpose of submissions

Each submission we receive makes an important contribution to our work and is read by Commissioners and relevant Royal Commission staff. Submissions are different to evidence that the Royal Commission receives at public hearings, and are used in different ways. Information in submissions informs our work in many ways, including to:

- identify the nature and extent of violence against, and abuse, neglect and exploitation of, people with disability
- better understand the systems and contexts in which violence, abuse, neglect and exploitation have occurred
- better understand the impacts on and experiences of people with disability, their families, support people and the Australian community
- gather information to support and direct our investigations, hearings and research programs
- develop a national understanding of complex social issues relating to violence against, and abuse, neglect and exploitation of, people with disability
- hear diverse views from people across Australia with a variety of disabilities, impairments and experiences
- better understand systemic issues faced by people with disability, their families and supporters
- identify themes to inform public hearings and policy development
- contribute to and inform the development of recommendations to influence change.

Submissions are also critical in ensuring the Royal Commission centres the voices of people with disability, and their families and supporters, in our work.

Different ways to make a submission

In line with our Accessibility and Inclusion Strategy (as outlined in Chapter 5, ‘Our organisation’) we have designed the submissions process to be as flexible as possible.

A submission can be made in any way the submitter is comfortable with. This includes:

- using a form available on our website, which can be filled in online or downloaded
- email
- paper hardcopy
- phone
- video or audio recordings (which are assessed and analysed in the same way as written submissions).

Other ways people have, or could, provide submissions include:

- through a format such as poetry, song or artwork
- with the assistance of an advocacy organisation funded by the Australian Government Department of Social Services to assist people engaging with the Royal Commission.

We provide guiding questions to help people prepare their submissions. These are available on the submission form and through the 'Share your story' section on our website.[1] Answering these questions is optional.

We are committed to ensuring our inquiry is accessible and accept submissions in any language, including Auslan and Indigenous languages. Information about making a submission has been translated into a number of languages and is available on our website.[2] People wanting information in their own language about making a submission are also able to access the Translating and Interpreting Service (see Chapter 6, 'Support for people engaging with the Royal Commission' for more information).

Support services for people making submissions

We encourage people to engage with available support services before, during and after making a submission. These services are independent of the Royal Commission, and include:

- Your Story Disability Legal Support, which provides free, independent legal support to people wishing to share their experiences with us
- phone and face-to-face counselling services
- advocacy services funded to provide advocacy support to people engaging with the Royal Commission, through the National Disability Advocacy Program (NDAP).

Further information about these and other support services is available in Chapter 6.

How submissions have changed

The Royal Commission invites and responds to feedback about all aspects of submissions. This is critical in ensuring our activities, processes and procedures are both trauma-informed and meet the needs of people with disability, their families, support people, advocates and organisations, as well as those of the Royal Commission. Our trauma-informed approach is discussed in more detail in Chapter 6.

We have changed the way we receive submissions as we have identified opportunities for improvement and responded to feedback.

The first submissions

We began accepting submissions on 29 July 2019. The optional submission form we provided at the time asked a number of guiding questions and collected basic demographic data such as age and gender. It could be downloaded in Word and PDF form. It was also available in Easy Read, a way of presenting information using words and pictures so it is easy to read and understand, particularly for people with cognitive disability. Due to the technical limitations of our temporary website, the first submission form could not be completed online.

Stakeholder feedback

We received feedback on the submission form from organisations and individuals. We also analysed the submissions process to make sure it met the needs of the community, stakeholders and the Royal Commission.

The feedback included:

- it would be helpful if we provided more direction on our areas of interest, given the broad and wide-reaching nature of our terms of reference
- the questions asked in the submission form were too complex and not in plain English
- the form was too complex
- the form did not have the option of identifying the subject and the author of the submission as different people
- an online form would be helpful
- the form should be clear on how and where the information would be used
- an online portal to upload video submissions was necessary because it was difficult to submit large video files via email.

Incorporating feedback

This feedback was invaluable in developing and transitioning to the current version of our form. In line with our Accessibility and Inclusion Strategy we redesigned the submission form, including adapting and varying the ways submissions can be made, to make the process more accessible.

The updated form went live on 13 February 2020 and supports the needs of the Royal Commission and individuals and organisations by:

- making clear that it is optional to answer any question or provide any information
- providing options for people to make a submission for themselves, for another person/s, for themselves and another person, or on behalf of an organisation
- allowing anonymous submissions through the online platform by not requiring any names or contact information
- asking fewer guiding questions
- using plain English
- asking the author for their consent for the Royal Commission to publish the information provided, as described in the 'Consent to publish' section.

After we revised the submission form, the Royal Commission wrote to disability advocates and peak bodies to invite feedback on the revised form by 28 May 2020. We received a limited amount of feedback which highlighted the importance of accessibility, simplicity and flexibility. We are currently considering this feedback.

The Royal Commission is grateful for all the feedback and the role stakeholders have played in developing the submission form and the broader submissions process.

Public use of submissions

The Royal Commission reads and gives careful consideration to all information it receives, regardless of whether the Royal Commission publishes that information either on the website or in other public documents prepared by the Royal Commission, for example in our interim and final reports. The Royal Commission may publish information that it receives, where a person has indicated that they consent to publication, and where the Royal Commission considers it appropriate to do so. However, the Royal Commission is not required to publish information it receives and, when we do, we do so in line with our legal obligations.

Consent to publish

To ensure we are genuinely working from a trauma-informed approach, choice and control over the publication of any personal experiences shared in a submission need to remain with the person sharing those experiences. As part of the revised submissions process, each individual is provided with information about how their submission could be used before they are asked to give their consent to use it. The Royal Commission will not publish or refer to information from a submission in any public document without the informed consent of the person or organisation making the submission.

The updated submission form includes a prompt for organisations and individuals to tell us if and how they want their information used. The options for people to select from, and what they mean, are:

- **‘Public – published on website’**. These submissions may be published on the website or in public documents, including the interim and final reports. Names and other identifying details may be included.
- **‘Anonymous – published on website’**. These submissions may be published on the website or in public documents, in de-identified form. (‘De-identified’ means names and any features that would identify the submitter or any other person within the submission are removed.)
- **‘Anonymous – not published on website’**. These submissions will not be published on the website, but may be used in a de-identified form in public reports or other public materials.
- **‘Restricted’**. These submissions will not be published in any way. These submissions will not be referred to in any public document.
- **‘Unsure’**. The Royal Commission will contact individuals who select this category to discuss their options or to refer them to independent support services for advice.

If someone gives consent to their submission being published on our website, the Royal Commission may do so where it considers it appropriate to do so. However, if the Royal Commission decides to publish a submission, there will be occasions where we may need to redact (block out) words it contains, in line with our legal obligations.

The Royal Commission may contact individuals or organisations who make submissions without using the submission form, or who made submissions before the consent options were included in the form, to seek their informed consent to public, anonymous or restricted use of the information.

Publishing submissions as de-identified narratives

Where the Royal Commission considers it appropriate to do so, we will publish information in submissions from individuals as de-identified narratives or ‘stories’. We may publish these narratives on our website, or in public reports or materials, depending on the consent option chosen. We only use submissions in this way if the submitter has chosen the ‘public’ or either of the ‘anonymous’ options described above.

Using narratives allows us to treat submissions in a uniform way, despite the variety of formats they are made in. For example, it will ensure that the experiences of those who make submissions via video or in languages other than English are published in the same way as those made in writing in English. Where a submission has been made in an alternative format, or in a language other than English, the Royal Commission will arrange for transcription and translation services. If appropriate, the narrative will then be translated into the original language for publication.

Narratives provide a public voice

Narratives provide an accessible and user-friendly way for us to communicate the breadth of people's experiences of violence, abuse, neglect and exploitation.

Many people in the Australian community may not be aware of, or understand, the experiences of people with disability and the extent of violence, abuse, neglect and exploitation they can experience over the course of their lives. By publishing organisations' submissions and de-identified individual narratives our inquiry can highlight and give voice to individual experiences of violence against, and abuse, neglect and exploitation of, people with disability.

Publishing submissions from organisations

We publish submissions from organisations on our website where we have their consent. Before doing so, we seek to ensure the organisation has itself obtained any relevant consent and appropriately de-identified any case studies included in its submission. We will also redact (block out) words if required, in line with the Royal Commission's legal obligations.

Confidentiality

Individuals may be concerned that including certain information or documents in a submission may breach a legal obligation to keep that information confidential, or may be defamatory. They may also be concerned about how we will keep information they provide in their submission confidential.

The Royal Commission encourages individuals to use the independent legal advisory service, Your Story Disability Legal Support, for help understanding their options in sharing their experiences. This service can also provide legal advice about the protections available under the *Royal Commissions Act 1902* for people who provide information to the Royal Commission. This can be helpful for individuals who are concerned about retribution or other consequences of providing information to us. Chapter 6 contains contact details for the Your Story Disability Legal Support service, as well as for other supports for people engaging with us.

More detailed information on the protections available to individuals engaging with the Royal Commission and the confidentiality of submissions is available in Chapter 4, 'Nature and powers of the Royal Commission'.

Snapshot of submissions

Summary of submissions received so far[3]

As at 31 July 2020, the Royal Commission had received 1237 submissions. Most of these were provided through email (783 submissions, or 63 per cent) or the online form (322, 26 per cent). We had received 93 submissions in hard copy, 36 over the phone, and three in person.

Of the 881 people who provided submissions about their own experiences or others', most people (61 per cent) wrote about their own experiences.[4] Others described the experiences of someone else (39 per cent). As a percentage of all submissions:

- 25 per cent were made by a parent or family member of a person with disability
- 5 per cent were from advocates of people with disability
- around 4 per cent were from organisations.

Around 48 per cent of people making submissions told us about the nature of their disability, or the disability of the person they were making the submission for.[5] For this group:

- around 42 per cent of submissions were from or about a person with psychosocial disability
- 40 per cent were from or about a person with a physical disability
- around 24 per cent were from or about a person with cognitive impairment
- 16 per cent were from or about a person with a sensory impairment.

This breakdown does not reflect the broader population of people with disability. For example, for adults aged 18 to 64 years, physical disability is most common, followed by sensory impairment (see Chapter 15, 'Nature and extent of violence against, and abuse, neglect and exploitation of, people with disability'). However, the breakdown of people we are hearing from and about through submissions is consistent with research we commissioned, which found that people with intellectual disability and/or psychosocial disability experience violence at higher rates than others in the community (see Chapter 15).[6]

Around 30 per cent of people, who told us where they or the person they were making the submissions for lived, were in New South Wales. Around 23 per cent lived in Queensland, and around 20 per cent lived in Victoria. See Figure 8.1 for a breakdown of this information. The breakdown of people making submissions by state and territory is roughly the same as the distribution of people with disability across Australia, with most people with disability living in NSW (31 per cent), followed by Victoria (25 per cent) and Queensland (22 per cent).[7]

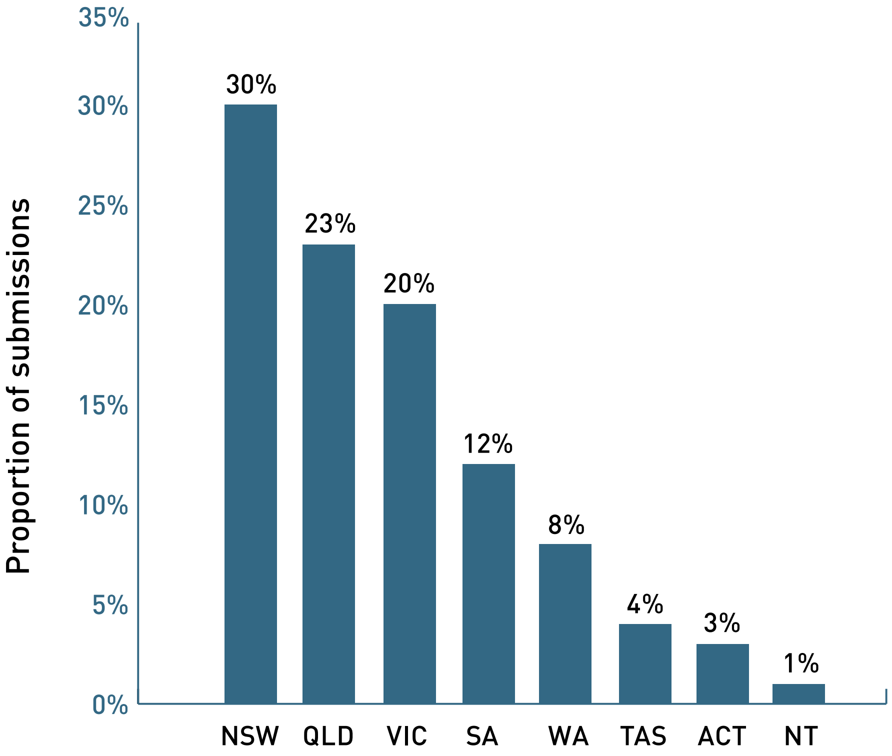

Figure 8.1: Proportion of submissions by state/territory

Most people making submissions (92 per cent) told us their gender, or the gender of the person they were making the submission for. For this group, 33 per cent of submissions were from or about a man, 63 per cent were from or about a woman, and 2 per cent were from or about somebody who was transgender, indeterminate or other. The gender breakdown of people making submissions is roughly the same as the gender breakdown of people with disability in Australia (see Chapter 15).[8]

Of those who told us their age, or the age of the person they were making the submission for:

- 10 per cent were under 18
- 51 per cent were aged 18 to 64 years
- 5 per cent were over 65 years.
- The remaining 34 per cent were of unknown age.

The age breakdown of people making submissions is different to the age breakdown of people with disability nationally. As described in Chapter 15, in Australia around 10 per cent of people with disability are aged under 18, 45 per cent are aged 18 to 64 years, and 45 per cent are aged 65 years or over.[9]

We received very few submissions from people who said they or the person they were making the submission for were people with disability from a culturally or linguistically diverse background, were First Nations people, or were LGBTIQ+.

Most submissions discussed a range of topics and issues. Most commonly, they raised issues related to education, and homes and accommodation for people with disability. They also raised issues relating to employment, interactions with the criminal justice system and health. Themes and issues emerging from information shared with the Royal Commission are discussed in more detail in Chapter 17, 'Emerging themes and key issues'.

Gaps in submissions

Our inquiry is committed to ensuring we hear from a broad range of people so as to build a comprehensive understanding of the issues and problems faced by people with disability, and their families and supporters.

We are aware there are groups of people in the community who won't have an opportunity to contribute their views and experiences without specific strategies to address barriers to participating. This may be due to their cultural background, where they reside, or their disability. We are particularly aware of barriers and challenges faced by people with disability and their families who:

- are First Nations people
- are from culturally and linguistically diverse backgrounds
- reside in closed institutions such as prisons, forensic mental health facilities and youth detention centres
- reside in segregated environments including specialist accommodation such as group homes.

The Royal Commission has to date not heard from or about these groups as much as we would like to. We understand the need to be proactive in our engagement to ensure their voices are heard and their experiences factored into our work. In this regard, we recognise the critical role of NDAP organisations in reaching out to people with a disability from diverse communities, and assisting them to engage with the Royal Commission.

Additionally, our community engagement work seeks to address some of the barriers to participation. (See Chapter 9, 'Community engagement' for more information.)

Timeframes for making submissions

There is currently no closing date for submissions to the Royal Commission. However, to ensure submissions about the experiences of people with disability contribute to our final report and recommendations, we will set a deadline. We will clearly communicate this date to the public well in advance and in a variety of ways.

Endnotes

1 ‘Share your story’, *Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability*. <https://disability.royalcommission.gov.au/share-your-story>

2 Arabic, Simplified and Traditional Chinese, French, Hindi, Samoan, Spanish, Tagalog and Vietnamese.

3 Data in this section is based on demographic information voluntarily provided in submissions to the Royal Commission. The Royal Commission does not require people making a submission to provide demographic data or information and any information provided is done at the discretion of the individual. As a result, these figures should be taken as representative only and are used to assist in forming an understanding of who the Royal Commission is hearing from through submissions. The demographic data is used only in a de-identified statistical manner and is not subject to the consent options outlined above. Data is stored and used in compliance with the Australian Privacy Principles.

4 A limited number of people have made more than one submission to the Royal Commission, such as where multiple Notices to Produce have been requested and provided by the Office of the Solicitor Assisting.

5 Some people who told us the nature of their disability indicated more than one impairment or disability group. Because of this, the proportions listed in the points below add up to greater than 100%.

6 Georgina Sutherland, Anne Kavanagh, Gwynnyth Llewellyn, Lauren Krnjacki, Sean Byars and Jen Hargrave, *Nature and extent of violence, abuse, neglect and exploitation against people with disability in Australia*, report prepared for the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, March 2020, p 11.

7 Australian Bureau of Statistics, *Disability, Ageing and Carers, Australia: Summary of findings, 2018,* Catalogue number 4430, October 2019, Table 4.1.

8 Australian Bureau of Statistics, *Disability, Ageing and Carers, Australia: Summary of findings, 2018,* Catalogue number 4430, October 2019, Table 1.3.

9 Australian Bureau of Statistics, *Disability, Ageing and Carers, Australia: Summary of Findings, 2018,* Catalogue number 4430, 24 October 2019. Results accessed using Australian Bureau of Statistics TableBuilder Age in single years up to 100 years and over by Whether has a disability.

Liza and Carol*

Liza has an intellectual disability and mild cerebral palsy. She's non-verbal and has limited communication, so her mum, Carol, told us Liza's story.

One day in the late 1990s, the manager of a nearby group home told Carol she had seen Liza, then nine years old, being restrained in a chair at her school.

Carol went to the school with a support worker, Caitlin, to find out what was going on. At the school they found a small red chair fitted to a wooden base. It had white plastic moulded inserts for feet, with velcro straps. Slots had been cut into the chair to feed through a waist band with a clip fastener. The school principal would later refer to it as a 'seatbelt'.

Carol and Caitlin went to collect Liza, who was in the playground. Through large windows they could see Liza try to come to them. Carol told us she saw a tall man roughly grab Liza's arm, stopping her from moving. When Liza fell, he dragged her along the veranda and onto a grassed area. He only let go of Liza when another staff member intervened.

Carol said she went to the police station to report this assault but the police told her they couldn't get involved in education department issues.

Caitlin, who saw the restraining chair and witnessed the abuse, wrote a letter of complaint to the school principal. The school principal responded with a letter of apology, in which he referred to following up on the restraining 'seatbelt'. The man who had abused Liza, who was a teacher's aide, also wrote a letter of apology.

'And that was it!' Carol said. 'People need to be dealt with in accordance with the law. If my daughter was dragged in any other situation the police would be involved.'

Liza had to return to the school. The teacher's aide went on stress leave, and Carol spent the next two years working on getting her daughter out of the school.

'Violence towards a person with a disability should be a hate crime,' said Carol.

*** Names changed and some details removed to protect people's identities. Narrative based on a submission to the Royal Commission.**

9. Community engagement

Key points

- This Royal Commission must engage with people with disability and the wider community in order to understand, increase awareness of, and change community attitudes towards violence against, and abuse, neglect and exploitation of, people with disability.
- Our Community Engagement team develops and implements accessible community engagement activities aimed at ensuring people with disability, their families, supporters, advocates and the broader community can participate in the inquiry.
- We have developed a Community Engagement Strategy, First Nations engagement principles, and culturally and linguistically diverse engagement principles, to guide our activities.
- Our community engagement activities include:
  - community forums for people to share individual experiences
  - information sessions about the Royal Commission's work and progress
  - culturally appropriate engagements with First Nations and culturally and linguistically diverse people with disability
  - other targeted engagements, for example with people with disability living in closed environments such as prisons
  - consultations with people with disability and advocates on specific focus areas
  - involving people with disability and advocates in developing activities that are best suited to their needs.
- Community engagement is a cumulative process and relies on building relationships and trust.
- In March 2020, the Royal Commission suspended face-to-face community engagement due to the COVID-19 pandemic. Engagement continued during this time via phone and videoconference with a range of stakeholders, including people with disability.

Introduction

Engaging with and listening and responding to a diverse range of people with disability, their families, supporters and advocates is a critical part of the Royal Commission's work.

People with disability are the experts on their own experiences. Sharing this expertise with us helps us understand the nature and extent of violence against, and abuse, neglect and exploitation of, people with disability, including the barriers and challenges individuals face. We also hope to gain insight into their visions for a better future. This will help inform our recommendations for sustainable change to reduce violence against, and abuse, neglect and exploitation of, people with disability.

This chapter outlines:

- our approach to community engagement, including its purpose and the principles and goals that guide our engagement activities
- our key community engagement activities as at 31 July 2020, and some activities planned for the future
- key insights and themes that have emerged
- our targeted engagement, including our engagement with:
  - cohorts specifically identified in our terms of reference – which include LGBTIQ+ people, First Nations people and culturally and linguistically diverse people with disability
  - other groups, including those whose disability, or physical setting and disability, may preclude or limit their opportunities to proactively engage with us.

Community engagement purpose and strategy

Ensuring we hear the experiences of people with disability is critical to our work. The purpose of our community engagement activities is to connect to people with disability, their families, advocates, support people, representative organisations and disability sector workers. By doing so we aim to increase their awareness of and encourage their contribution to our work. The Royal Commission will undertake engagements in every state and territory, including in capital cities and regional and remote communities. The Royal Commission engages with people with all types of disability, including cognitive impairment and physical, sensory, intellectual and psychosocial disability.

We have developed a Community Engagement Strategy that is based on best practice, as outlined by the International Association for Public Participation Australasia (IAP2), including in its public participation spectrum.[1] IAP2 is the peak body for, and advocates best practice in, community engagement and public participation.[2] The strategy is available on our website.[3] It explains:

- the purpose of community engagement
- focus areas for community engagement
- who we engage with
- how we engage with people.

Our principles and goals

The Community Engagement Strategy includes a set of principles and goals that guide our community engagement work. These are listed in Box 9.1 and Box 9.2.

Box 9.1: Core engagement principles

- Engagement reaches out to and is accessible for people with disability and acknowledges their broad range of experiences.
- Engagement is trauma-informed.
- Engagement methods are inclusive and meet the particular needs of individuals, groups and communities.
- Engagement is mutually respectful, open and honest.
- Engagement is timely and accurate.

Box 9.2: Community engagement goals

Goal 1	Goal 2	Goal 3	Goal 4
To listen to and build positive relationships with people with disability, their families, advocates and supporters.	To promote and facilitate access to the work of the Royal Commission, and collaborate and consult on key issues.	To involve people with disability and other key stakeholders in co-designing and delivering engagement strategies and activities.	To conduct engagement activities that deliver insights and information to assist the Royal Commission with its work.

Our activities

In this initial stage of the Royal Commission, our community engagement activities have mainly consisted of:

- community forums
- information sessions
- meetings
- presentations.

These activities, and our planned future activities, are described below. As we continue to work alongside and draw on the expertise of people with disability, their families and advocates, we anticipate being able to expand on these methods. Community engagement is a cumulative process and relies on building relationships and trust.

Disability Strategic Engagement Group

To enhance engagement with the disability sector, the Royal Commission has established a Disability Strategic Engagement Group (DSEG).

The DSEG is co-chaired by two Commissioners who are leaders in the disability community:
Dr Rhonda Galbally AC and Mr Alastair McEwin AM. Membership includes Commissioner Roslyn Atkinson AO, the Royal Commission's Official Secretary, senior staff from the Royal Commission, our three senior advisors, Mr Maurice Corcoran AM, Emeritus Professor Ron McCallum AO and Associate Professor Lorna Hallahan, and three external members. In total, eight members are people with disability. The external members were chosen based on their experience in a leadership role within the disability community and their expertise in engagement with people with disability. They are:

- Ms Janet Meagher AM
- Ms Rosemary Kayess
- Ms Judy Huett.

The first meeting of the DSEG is planned for late August 2020. Information on the DSEG is available on our website.[4]

Our engagement with advocacy groups and representative organisations

Successful community engagement relies on developing positive relationships and goodwill with a range of stakeholders in communities. Our early and frequent engagement with a diverse range of stakeholders in the disability sector – including advocacy groups and other organisations that support people with disability – has allowed us to:

- raise awareness and understanding about our purpose, terms of reference, functions, structure and limitations
- inform organisations of how they and the people they represent can participate in the work of the Royal Commission and share their experiences with us

- keep the sector updated on our progress, including that engagement activities were underway, where we hold our activities, key pieces of work we have completed, and future events
- provide information about our policy and research work and explain our legal processes
- use the concerns, questions and suggestions from stakeholders to improve our approach across the Royal Commission, including how we include people with disability in our work
- build relationships with key organisations and individuals to create opportunities for future consultation, collaboration and co-design work.

Community forums

Community forums are one of the ways we hear about individual experiences of violence against, and abuse, neglect and exploitation of, people with disability.

Community forums have further benefits, including:

- empowering people with disability, their families and advocates to speak about their experiences
- raising the awareness of other participants and the broader community about violence against, and abuse, neglect and exploitation of, people with disability
- providing opportunities for participants to build connections, both with each other and with the Royal Commission
- identifying issues for further investigation and potential witnesses for hearings.

Community forums we have held

The Royal Commission is committed to conducting community forums in all states and territories, and in different location types, including capital cities and outer-metro and regional areas. This is to ensure we are hearing about issues that might impact people in those location types differently. In selecting locations, we look at available data on:

- the total population, and the number and percentage of people with 'profound or severe disability' (as defined by the Australian Bureau of Statistics)
- the number of carers in a location
- the number of First Nations people with disability, and the total percentage of the location's population who are First Nations people
- the number and percentage of the location's population who were born in a predominantly non-English speaking country.

More than 560 people registered to attend the eight community forums we held between September 2019 and February 2020. We estimate that more than 600 people attended in total. The forums were held in six locations, in metropolitan and regional Australia (see Figures 9.1 and 9.2).

Eighty-seven speakers shared their experiences of violence, abuse, neglect and exploitation with us. Of these, 26 speakers were people with disability; 34 speakers were parents of children with disability; three were siblings of people with disability; 10 were support people for adults with disability; and 12 were advocates for people with disability. We also heard from two parents whose children had passed away. We thank all speakers for their willingness to share their experiences and to all participants for spending time engaging with us.

The Royal Commission does not specifically ask for demographic information from people who register to attend our community forums. However, only a small number of speakers identified as being First Nations people and people from culturally and linguistically diverse backgrounds. The Royal Commission is committed to ensuring the experiences of these and other priority groups are heard and is undertaking more targeted engagement to facilitate this. We say more about this later in this chapter, in ‘Our targeted engagement’.

Figure 9.1: Locations of community forums (September 2019 – February 2020)

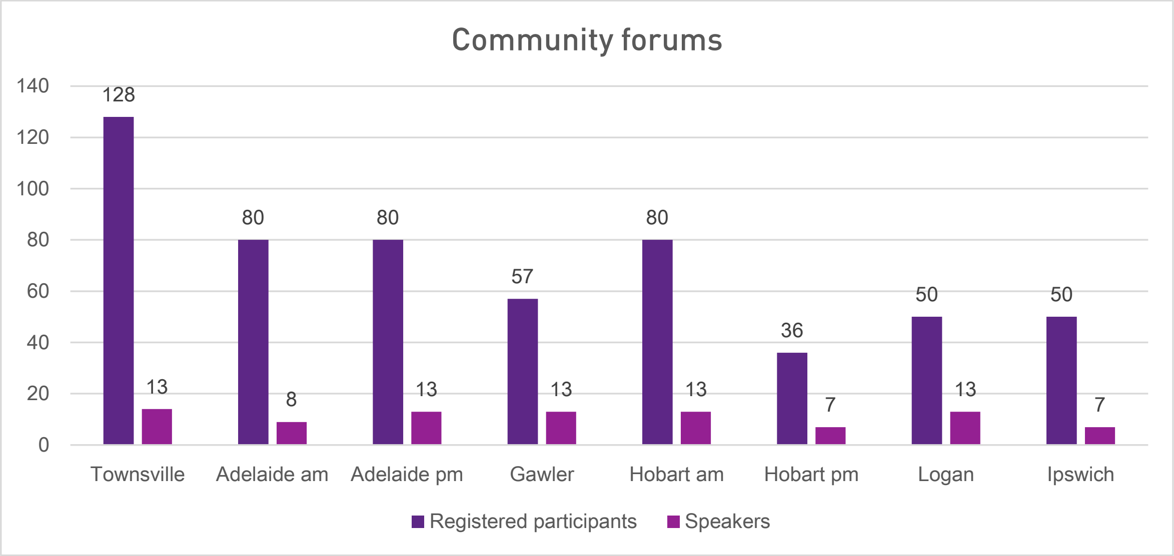

Figure 9.2: The number of registered participants and speakers at community forums

Accessibility, inclusion and safety

Our main priorities when we run community forums is to ensure they are accessible, inclusive and take a trauma-informed approach. We say more about our trauma-informed approach in Chapter 6, ‘Support for people engaging with the Royal Commission’.

We assess potential venues in each community forum location for their accessibility. This includes assessing mobility access, the ease of finding them, and provisions for assistance animals. We also consider parking and public transport and how central each location is to ensure as far as possible that venues are convenient for people to attend.

We also:

- ensure our event registration processes are accessible and flexible, with options including Event Brite, phone or email
- offer session times in both the morning and evening to account for different preferences and schedules
- provide separate ‘break out’ spaces for use by attendees and counselling teams who may want time away from the forum
- ask local First Nations Elders to perform Welcome to Country
- use appropriate audio-visual technology, including closed captioning and hearing loops, to ensure all attendees can follow the proceedings as easily as possible

- ensure Auslan interpreters attend all forums to provide interpreting services for the Deaf community before, during and after the forum
- contact registered speakers before and after forums to discuss options for sharing experiences and to seek feedback
- provide speakers with a written guide on the forum process, and to help with preparing their statement.

Royal Commission staff members are available to provide information and support to participants and speakers before, during and after each forum. This includes counselling and support staff; community engagement staff; First Nations and culturally and linguistically diverse engagement officers; staff from our policy and research, submissions and private sessions teams; staff from the Office of Solicitor Assisting; and media and communications staff.

Continuous improvement

We are continuously improving our community forums based on feedback. For example, following feedback from advocates and participants about the danger of re-traumatisation for people sharing their experiences we only now invite people with disability, their families and advocates to attend. This aligns with our commitment to the principles of trauma-informed practice.

As part of our commitment to putting people with disability at the centre of our work, our seventh and eighth community forums, in Logan and Ipswich in south-east Queensland, showcased the talents of people with disability. It was a privilege to have a group of local young musicians, the King Stones, perform.

Emerging themes from community forums

Community forums encourage and support people to share individual experiences. This helps us identify emerging themes among diverse groups of people. Some themes that have emerged at this early stage, and which are discussed further below, are:

- the need for better regulation, oversight, transparency and accountability
- the barriers to self-advocacy
- control, autonomy, disempowerment and discrimination
- the role and recognition of families
- issues with the accessibility and responsiveness of service systems.

Regulation, oversight, transparency and accountability

Some speakers told us about their experiences in group homes and in institutions such as hospitals, respite care centres and schools. They said there was a need for enhanced training, oversight and regulation of service providers, education providers and the government bodies responsible for providing and regulating services. Speakers said this was particularly important in preventing and responding to reports of violence against, and abuse, neglect and exploitation of, people with disability. Several speakers expressed that they felt their experiences were dismissed when they complained to providers, schools, regulators or police. Some speakers told us that police declined to pursue further action because they said the person with disability would not be considered a credible witness.

We also heard from participants of a culture of ‘empty’ talk regarding regulation and protection mechanisms. Some speakers expressed disappointment that some rights contained in international human rights instruments were not implemented in domestic law, policy and practices. Speakers told us about their experiences with systems and regulatory bodies created to provide an avenue where people could escalate complaints and concerns. These included state and federal human rights and anti-discrimination commissions and ombudsmen, as well as internal complaint mechanisms established by service providers and government departments. Some speakers told us they felt these mechanisms were failing people with disability and their families. We heard that new systems such as the National Disability Insurance Scheme (NDIS) have not remedied these concerns.

We heard mixed views from speakers about the NDIS and the National Disability Insurance Agency (NDIA). Some speakers told us about the positive impacts that the NDIS had had on their lives. However, many more highlighted that their experiences of the NDIS did not meet their expectations, both in its design and implementation. Some people said that in their view the NDIS’s emphasis on giving people with disability choice and control was undone because:

- the NDIA acted as ‘gatekeeper’ on how people with disability live their lives
- some providers of disability services saw people with disability as a ‘commodity’.

We heard that these two factors did not support choice and control for people with disability, or quality service provision, and reinforced a sense of disempowerment for participants in the scheme.

Barriers to self-advocacy

When discussing regulation, many participants shared a strong view that the current systems (including the NDIS and complaint mechanisms referred to above) do not support self-advocacy. Some speakers told us that family members with disability living in supported accommodation experienced human rights violations, including over-medication, failure to provide medication and indoctrination into religion. They described how they struggled to advocate for their loved ones in these settings, which was compounded by a lack of housing options. They spoke about how they had looked forward to the NDIS providing more freedom, choice and control but felt that they had been let down as the complexity of the NDIS system was intimidating and difficult to navigate.

Some speakers said there were risks for people with disability and their families when they speak up for themselves. Speakers told us they feared or had experienced punishment from people in positions of power, such as employers, school principals and service providers. For example, some parents of children with disability told us they had been prevented from attending their child's school, in their view because they made regular complaints to or about their child's teacher. Others said there was a blaming culture where service providers or schools made the parent feel their demands in relation to their child's education were unreasonable. For example, parents spoke of being labelled 'that parent' when advocating for their children at school. Some speakers said that in their view regulatory and complaints systems were inaccessible and lacked transparency and accountability.

Self-determination, autonomy, disempowerment and discrimination

The struggle for self-determination (control over one's life) and feelings of disempowerment were strong themes at many forums.

Speakers talked about disempowerment and discrimination in a range of settings.

Examples include:

- institutional practices, and a lack of person-centred care in institutions and other accommodation settings
- 'restrictive practices' (physical, mechanical, chemical, environmental and psychosocial restraints on a person with disability, and seclusion), their use and oversight mechanisms
- a lack of choice and control in living arrangements and by having 'assigned' support workers
- language deprivation from a lack of exposure to or accessibility of spoken or sign language during language acquisition years, and not being able to use the language preferred (such as Auslan)
- discrimination in the workplace that made it difficult to gain and keep a job
- barriers to employment for culturally and linguistically diverse people with disability
- judgmental attitudes about the ability of people with disability to make decisions
- labelling and criminalisation of some behaviour traits that may be perceived as aggressive or confrontational, particularly by those in authority such as police or security guards
- inappropriate prescription of and overuse of drugs by some in the health system, including treating people with disability with drugs against their will

- violence and abuse by members of the community against people with disability trying to go about their daily lives.

Role and recognition of families

A number of parents and family members of people with disability spoke of the impact that a caring role has on them as individuals and on the family as a whole. In particular, families said that in their view governments and society did not recognise and value the intensity of being a carer and its effect on their social participation and economic independence.

Many parents of school-aged children with disability said they were frustrated by the education system and its inability to support their child's needs in a consistent way. They emphasised the important 'parent advocate' role they play in asking for their child to be included, treated equally, have their behaviour managed appropriately, and have their basic accessibility needs met at school. Many parents said they found schools were unable or unwilling to respond to these requests.

Accessibility and responsiveness of service systems

Some speakers said various service systems – health, mental health, education, employment, disability, social services and justice – have inadequacies when it comes to people with disability. This was raised in multiple forums, particularly in regional and rural areas.

Specifically, speakers said that service systems:

- have poor or out of date knowledge of disability
- were unwilling to change
- provided poor responses to the changing individual needs of a person with disability as they aged
- provided a small range of poor quality services, which limited the choices of people with disability
- were inconsistent with one another.

Information sessions and presentations

The Royal Commission has conducted information sessions and given presentations to a large number of organisations and their members, including advocacy and disability representative organisations, public guardians and public advocates, service providers, and First Nations and multicultural organisations and communities. The purposes of these sessions has been to:

- introduce the Royal Commission
- provide information about the Royal Commission and how people with disability can engage with us
- provide updates on the Royal Commission's work, including upcoming events, hearings, and release of issues papers
- answer questions.

Our targeted engagement

The Royal Commission's terms of reference require us to look at the particular situations of First Nations and culturally and linguistically diverse people with disability.[5]

The Royal Commission has developed principles to guide our engagement with First Nations people with disability and principles for engaging with people with disability from culturally and linguistically diverse communities. Both sets of principles are informed by international human rights instruments, including the:

- United Nations *Convention on the Rights of Persons with Disabilities* (*CRPD*)[6]
- United Nations *Declaration on the Rights of Indigenous Peoples* (*UNDRIP*)[7]
- *International Convention on the Elimination of All Forms of Racial Discrimination*[8]
- *International Covenant on Civil and Political Rights.*[9]

The principles are also informed by our Accessibility and Inclusion Strategy which is available on our website.[10]

Engaging with First Nations people with disability

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.

The Royal Commission respects these systems and takes a flexible approach to how we engage with First Nations people. We ensure that our engagements are culturally appropriate and take into account the relevant protocols, languages, capacity and leadership of existing First Nations governance structures. This includes seeking to engage with the relevant cultural leadership where appropriate, such as Elders and traditional custodians, in an effort to acknowledge, seek out and respect 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, the Royal Commission seeks to create an environment in which a range of different voices can be heard, and in the way they prefer to be heard, whether spoken, signed, gestured or requiring Auslan or First Nations language interpreters.

Applying the First Nations engagement principles to our work means the Royal Commission:

- **Applies a disability-led approach** – the voices, perspectives and experiences of First Nations people with disability are central to our work.
- **Ensures a rights-based framework** – we recognise and respect the human and civil rights of First Nations people with disability.
- **Ensures that engagements are culturally appropriate, safe and trauma informed** – we recognise and respect the culturally diverse needs and experiences of First Nations people with disability, and create culturally, emotionally and physically safe environments for people to engage with the Royal Commission.
- **Supports a strengths-based approach** – the Royal Commission recognises the inherent strengths of First Nations cultures and will be guided by the priorities and aspirations of First Nations people.
- **Respects self-determination** – the Royal Commission respects 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.
- **Is participatory, accessible and responsive** – the Royal Commission will take steps to ensure our processes promote culturally safe and inclusive participation.

In developing these engagement principles, we acknowledge the ongoing role that First Nations systems of law and governance, often found in First Nations community controlled organisations, continue to play and their significance in providing a culturally safe environment for those who engage with the Royal Commission.[11]

The First Nations engagement principles are available on our website.[12]

First Nations Peoples Strategic Advisory Group and community engagement team

The Royal Commission established the First Nations Peoples Strategic Advisory Group (FNPSAG) in early 2020. The FNPSAG comprises seven community experts who, together with Commissioner Andrea Mason OAM and Commissioners Roslyn Atkinson AO, Dr Rhonda Galbally AC and Mr Alastair McEwin AM, provide collective advice and leadership on matters relating to First Nations people with disability.

The seven community members are:

- Ms Joanna Agius OAM
- Ms Jody Barney
- Mr Jake Briggs
- Mr Damian Griffis
- Dr Jackie Huggins AM FAHA
- Dr Hannah McGlade
- Ms Louisa Uta.

In carrying out its work, the FNPSAG is guided by:

- the voices of First Nations people with disability, along with their families, supporters and advocates
- the experiences of First Nations people with disability
- specialist knowledge of considerations that are specific to First Nations people with disability
- the *CRPD*[13] and *UNDRIP*.[14]

The FNPSAG has met three times (2 March, 19 June, 21 July), with two further meetings planned for later in 2020.

First Nations community engagement team

We understand the importance of employing First Nations staff at the Royal Commission, to provide critical expertise, community links and knowledge in everything we do. In addition to the broad leadership role Commissioner Mason plays for the Royal Commission in general and for First Nations issues in particular, the Royal Commission has First Nations staff in all areas of our work, including policy and reporting, media and communications, legal, community engagement, private sessions and counselling.

Our engagement so far

The Royal Commission is engaging with and working alongside First Nations people with disability, their families, support people, advocates and communities.

In seeking to understand the experiences of First Nations people with disability of violence, abuse, neglect and exploitation, we also want to understand the uniqueness, complexity and diversity of First Nations communities and how the term 'disability' is understood by First Nations people.

First Nations people experience disability at a higher rate than the wider community.[15] Compared to First Nations people without disability, First Nations people with disability are also more likely to experience problems accessing support services.[16]

Our First Nations Community Engagement team has engaged with a diverse range of organisations that support First Nations people with disability in both metropolitan and regional locations. This has included meeting with First Nations community controlled organisations and members in Logan and Ipswich (in south-east Queensland), Darwin and Alice Springs. Commissioners and the team have also spoken to people in the Queensland communities of Bwgcolman (Palm Island) and Cherbourg, and Warumpi (Papunya) in the Northern Territory. Throughout these engagements we heard of experiences that highlight the disproportionate challenges faced by First Nations people with disability and the need to provide equitable access to services in ways that are culturally appropriate, as defined by First Nations people with disability.

We have identified several emerging themes through our engagement. These cover advice to the Royal Commission about our engagement, as well as organisations' views on what gives rise to violence against, and abuse, neglect and exploitation of, First Nations people with disability.

Advice to the Royal Commission about our engagement and communication with First Nations people with disability has included:

- Western concepts of disability need to be reframed and redefined to reflect First Nations cultures and focus on strengths.
- Research is needed to find 'cultural evidence' of how First Nations people understand disability. (This is a key element of the Royal Commission's research agenda as discussed in Chapter 11, 'Research and policy'.)
- The Royal Commission's communication should be culturally safe and reflect First Nations peoples' ways of doing business.

Organisations also told us about matters they thought gave rise to, or exacerbated, the experiences of First Nations people with disability of violence, abuse, neglect and exploitation. They include:

- A lack of early diagnosis, assessment and support can mean people with disability have their needs neglected. Some organisations told us this compounds or can lead to health and education needs not being met, and even interaction with the justice system. They said early diagnosis, assessment and referral for support are needed to reduce the impact of health and chronic health issues, although some raised concerns about labelling giving rise to discrimination.
- Service systems such as health, mental health, education, employment, disability, social services and justice are too complex and need to be simplified. We were told this complexity means some First Nations people with disability who need support may not access it, leading to their needs being neglected.
- Many service systems do not meet the needs of First Nations people with disability and need to improve. Some organisations told us that even when attempts were made to access support, the support was not always available. This could result in neglect, particularly if the person had no other informal supports willing or able to meet their requirements.
- Organisational and community capacity and capability needs to be built in urban, regional and remote communities so that First Nations people can access culturally appropriate services that meet individual and community needs. Some organisations feel that local knowledge and capability should be developed and used to further support and encourage access. They said the lack of these services can result in First Nations people declining services. In the absence of other suitable informal supports, this can lead to neglect.

Chapter 18, 'First Nations people with disability', provides a more detailed discussion of what we have heard in our work to date, including about what it means to live as a First Nations person with disability in Australia.

Engaging with culturally and linguistically diverse people with disability

Culturally and linguistically diverse engagement principles

The Royal Commission is committed to ensuring our engagement with culturally and linguistically diverse people with disability is inclusive and culturally appropriate. We have developed engagement principles to guide meaningful engagement with and reflect our priority of giving a voice to culturally and linguistically diverse people with disability.

The Royal Commission invited culturally and linguistically diverse representative and service provider organisations to provide comments on our draft engagement principles.[17] Following this, we held a roundtable by videoconference with a number of stakeholders[18] on 26 May 2020, led by Commissioners Atkinson, Bennett and McEwin. In addition to discussing the engagement principles, participants provided insights into and advice on our future engagements with culturally and linguistically diverse people with disability.

The culturally and linguistically diverse engagement principles are on our website.[19]

Our engagements so far

Our engagements with culturally and linguistically diverse people with disability have focused on sharing information, and presenting to multicultural forums and community leaders. We acknowledge the significant support for our engagements from advocacy groups, service providers, community leaders and members of culturally and linguistically diverse communities.

As at 31 July 2020, the Royal Commission had conducted more than 80 engagements with culturally and linguistically diverse individuals, community leaders, advocates and organisations across various locations, in all states and territories. These have enabled us to raise awareness of and share information about our work, and to encourage and facilitate engagement by culturally and linguistically diverse people with disability.

The people and organisations we have engaged with have shared their knowledge of and concerns about the challenges and barriers faced by culturally and linguistically diverse people with disability. What they have told us has reinforced the need for ongoing targeted activities to ensure we understand their unique experiences. These stakeholders raised a number of issues with us, including:

- Among culturally and linguistically diverse people with disability there is a lack of awareness and understanding of the Royal Commission and its relevance to them, to multicultural communities and to the multicultural sector.

- We need to provide a diverse range of accessible information, including material that explains Western concepts of disability and explains the external support services available to assist people engaging with the Royal Commission.
- Some culturally and linguistically diverse people with disability distrust governments and fear they will be punished if they speak out about their experiences of violence, abuse, neglect and exploitation. This can be because of past and current experiences, both overseas and in Australia, and restricts their ability to self-advocate.
- Culturally specific beliefs and norms influence whether culturally and linguistically diverse people with disability can or will access support services outside of family and community.
- Migration pathways and visa eligibility also influence whether culturally and linguistically diverse people with disability can or will access support outside of family and community.
- The concepts of ‘disability’, ‘abuse’, ‘neglect’ and ‘exploitation’ are not always easy to translate and are not commonly discussed in some culturally and linguistically diverse communities.
- Many culturally and linguistically diverse people with disability do not have a formal diagnosis.

We were also told that some culturally and linguistically diverse people with disability think the Royal Commission lacks diversity because a commissioner from a culturally and linguistically diverse background was not appointed. This feedback reinforces the need for the Royal Commission to work particularly hard to build relationships with culturally and linguistically diverse people with disability.

We have heard that many members of the Deaf community consider themselves to be culturally and linguistically diverse, with Auslan their community language. One of the Royal Commission’s seven Commissioners, Commissioner McEwin, is Deaf.

The feedback we have received highlights the need for the Royal Commission to undertake more targeted engagement with culturally and linguistically diverse people with disability, including women and young people. We will continue working with culturally and linguistically diverse people with disability, community leaders, representative organisations and advocacy groups to encourage their involvement in our work. This will help us better understand the diverse experiences and views of culturally and linguistically diverse people with disability.

Other targeted engagement

In addition to First Nations and culturally and linguistically diverse people with disability, who are referred to specifically in our terms of reference, our Community Engagement Strategy identifies a number of groups we believe require a multi-layered approach to engagement. Our Community Engagement team has carried out or is planning engagement activities to increase the voice of groups including:

- people with disability living in closed environments such as prisons, youth detention centres and forensic disability and mental health facilities
- people with disability living in segregated environments such as group homes, attending day programs or engaged in segregated employment (such as Australian Disability Enterprises)
- people with intellectual and cognitive disability
- young people with disability
- women and girls with disability.

Our engagement with people with intellectual and cognitive disability

Our work with advocacy organisations suggests that people with cognitive disability need better access to the Royal Commission. To meet this need, our Community Engagement team and our Policy, Research, Reporting and Data branch undertook a project, with advice from an advocacy organisation. This project recognised that people with disability are experts in their own experience. Its purpose was to:

- hear directly from, and broaden our understanding of, the experiences of people with cognitive disability on important issues, such as autonomy and decision making
- provide a framework for how we learn from people with cognitive disability about their visions for systemic change.

We had planned to engage with a focus group of people with cognitive disability on 18 March 2020, in Launceston, Tasmania, after holding a community forum and information sessions. We had designed this engagement using a co-design model, collaborating with an advocacy organisation and a self-advocacy group. Due to the COVID-19 pandemic and the suspension of all Royal Commission face-to-face engagements, this was postponed along with the community forum and information sessions. In consultation with the advocacy organisation, this engagement was held on 20 May 2020 using an online videoconferencing platform. This followed feedback that the participants were keen to proceed, particularly as it was a way of feeling connected during a time of isolation due to the COVID-19 restrictions. The focus group provided participants with an opportunity to share their experiences and insights about emergency planning and responses, including on the impact of the COVID-19 pandemic. These included:

- confusion around government messaging, including whether they were allowed to leave the house during the pandemic
- experiences of stigma and discriminatory attitudes
- feelings of isolation and exclusion
- a lack of choice and control.

The discussion provided useful insights on the Royal Commission's issues paper on emergency planning and responses[20] and was a feature article in our 'Connect' newsletter on 2 June 2020.[21]

We also held a similar focus group with a group of women with cognitive and learning disability on 29 July 2020 in Brisbane to discuss their experiences and ideas on issues including:

- relationships, domestic and family violence and sexual violence
- justice and experiences within the criminal justice system
- parenting.

Similar engagement mechanisms are being planned for young people with disability and culturally and linguistically diverse young people with disability. Our aim is to expand and adapt this project to include other groups.

Our engagement with people with disability in closed and segregated environments

As noted, our terms of reference require the Royal Commission to inquire into violence against, and abuse, neglect and exploitation of, people with disability in a range of settings.[22] We will be engaging with people with disability in prisons, forensic mental health and forensic disability facilities, and youth detention centres. We will take a national approach to this engagement. This work is just starting but we have spoken formally with state and territory governments to seek their support to access these facilities.

The Royal Commission is also committed to engaging with people in environments such as group homes, day programs and segregated employment settings (including Australian Disability Enterprises). We recognise that people in these settings may experience greater difficulties in proactively engaging with us, and that we will need to go to them. This may be due to either the setting or the nature of their disability. Ensuring the voices and experiences of people in these settings are heard is of paramount importance, and is a priority for the Royal Commission. We intend to work closely with disability advocates and seek their assistance in supporting this work. We are refining our engagement strategy so that we can capture the experiences of people with disability in these environments in a safe and supported way.

Endnotes

1 International Association for Public Participation, *IAP2 Public Participation Spectrum*, 2019.

2 International Association for Public Participation, *IAP2 Public Participation Spectrum*, 2019.

3 Community Engagement Strategy, Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, September 2020.' <www.disability.royalcommission.gov.au/publications/community-engagement-strategy>

4 'Disability Strategic Engagement Group', *Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability*, webpage. <www.disability.royalcommission.gov.au/about-royal-commission/how-we-work/disability-strategic-engagement-group>

5 *Letters Patent* (Cth), 4 April 2019 amended 13 September 2019, (g).

6 *Convention on the Rights of Persons with Disabilities*, opened for signature 30 March 2007, 999 NTS (entered into force 3 May 2008).

7 *United Nations Declaration on the Rights of Indigenous Peoples*, GA Res 61/295, UN GAOR, 61st sess, 107th plenary meeting, Agenda Item 68, Supp No 49, UN Doc A/RES/61/295 (2 October 2007) annex ('*United Nations Declaration on the Rights of Indigenous Peoples*').

8 *International Convention on the Elimination of All Forms of Racial Discrimination*, opened for signature 21 December 1965, 660 UNTS, 771 (entered into force 23 March 1976).

9 *International Covenant on Civil and Political Rights*, opened for signature 16 December 1966, 999 UNTS 171, (entered into force 23 March 1976).

10 Accessibility and Inclusion Strategy, Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, August 2019. <www.disability.royalcommission.gov.au/publications/accessibility-and-inclusion-strategy>

11 First Nations Engagement Principles, Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, June 2020. <www.disability.royalcommission.gov.au/publications/first-nations-engagement-principles>

12 First Nations Engagement Principles, Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, June 2020. <www.disability.royalcommission.gov.au/publications/first-nations-engagement-principles>

13 *Convention on the Rights of Persons with Disabilities*, open for signature 30 March 2007, 999 UNTS (entered into force 3 May 2008).

14 *United Nations Declaration on the Rights of Indigenous People*, GA Res 61/295, UN Doc A/RES/61/295 (2 October 2007, adopted 13 September 2007).

15 Australian Bureau of Statistics, *National Aboriginal and Torres Strait Islander Health Survey, Australia, 2018–19*, Catalogue number 4715, 11 December 2019, Table 4.3.

16 Australian Bureau of Statistics, *National Aboriginal and Torres Strait Islander Health Survey, Australia, 2014–15*, Catalogue number 4714, 27 March 2017.

17 The invited organisations were: National Ethnic Disability Alliance, Federation of Ethnic Communities Council Australia, Forum for Australian Services for Survivors of Torture and Trauma, Multicultural Youth Network, Settlement Council of Australia, Refugee Council of Australia, Australian Multicultural Foundation, Multicultural Mental Health Australia, Migration Council Australia (Harmony Alliance and Young Migrant and Refugee Women's Advisory Group), Community Hubs Australia, Multicultural Centre for Women's Health, Centre for Disability Research and Policy (Disability and Multiculturalism stream) – University of Sydney, Multicultural Australia (Qld), Settlement Services International (NSW), Australian Red Cross Society (ACT/NSW/WA), AMES Australia, Melaleuca Refugee Centre (NT), Multicultural Disability Advocacy Association, AMPARO (Qld), Diversity and Disability Alliance (NSW), Ethnic Disability Advocacy Centre, Action on Disability within Ethnic Communities (Vic).

18 National Ethnic Disability Alliance, Federation of Ethnic Communities Council Australia, Forum for Australian Services for Survivors of Torture and Trauma, Multicultural Youth Advocacy Network, Settlement Council of Australia, Australian Multicultural Foundation, Migration Council Australia (Harmony Alliance and Young Migrant and Refugee Women's Advisory Group), Multicultural Centre for Women's Health, Multicultural Australia, Settlement Services International, Australian Red Cross Society (ACT/NSW/WA), AMES Australia (SA, Tas, Vic), Melaleuca Refugee Centre, Multicultural Disability Advocacy Association, AMPARO, Ethnic Disability Advocacy Centre, Action on Disability within Ethnic Communities.

19 Culturally and Linguistically Diverse Engagement Principles, Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, August 2020. <https://disability.royalcommission.gov.au/publications/culturally-and-linguistically-diverse-engagement-principles>

20 Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, *Emergency planning and response issues paper*, April 2020.

21 Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, 'Connect', e-newsletter, 2 June 2020.

22 *Letters Patent* (Cth), 4 April 2019 amended 13 September 2019, (g).

Niles and Tessa*

> It shames and saddens me how uneducated jail [staff] are about people with a disability. It's time the government realises, as a community we all have to make change happen.

Niles lost sight in his right eye as a consequence of a firearm injury. The damage included permanent cognitive issues and medical conditions, such as seizures, that require medication. He also required surgery to fix a medical plate. His mother, Tessa, made a submission about her son's experience as a prisoner with disability and her battles on his behalf:

> I saw him in a state I find hard to write [about] – in a wheelchair, his left eye bulging and moving round and he could not see.
>
> He was pushing his wheelchair into a wall and there were three guards present before Niles was taken to the hospital. He was vomiting and dizzy, no observations were done – bloods especially, with his condition.
>
> I [tried] all avenues to get help. [The prison guards] called him a 'retard' and he was put out in the yard while in his wheelchair without a helmet. At that time Niles had no plate put in [to repair his skull] so anybody could have hurt him.

Following the procedure to fit a plate to Niles's skull, Tessa said, he was sent back to prison before it was safe. She said Niles should not have been forced to return to prison without authorities considering the advice of his medical practitioners.

'His neurosurgeon said he should never had been taken from rehab,' Tessa said, as doing so would give Niles 'a 10 per cent chance of survival.'

Tessa told us she thinks prison staff are not adequately trained, and are certainly not interested in maintaining the level of vigilance and care required.

'He went down as soon as he was taken from rehab. He was doing good [in rehab]. Nobody understands the damage [done] is worse in jail.'

Tessa told us she believes that Niles was 'poisoned' with seizure medication while in prison, by guards both under- and over-medicating him. The resultant toxicity of medications in his system was so damaging that he became legally blind in his remaining eye, she said:

> One of the prison guards asked me not to say that she told me that Niles' meds were given to him in [wrong] doses and would be on the [prison] cameras.
>
> There's times Niles didn't get medications [but] his medical chart shows signatures [indicating that medicine was given] ... and [prison staff] never help with paper work now he is legally blind due to the toxicity of medication [the prison was providing].

'Before [prison] Niles was writing and reading, now [it's] just a blur,' said Tessa. She told us Niles has been waiting more than two years for an artificial eye.

Tessa is also angry about the lack of clarity in communication she continues to experience while dealing with her son's health and wellbeing.

She would like to see prisons staffed 'with professionals in all areas' so that true rehabilitation of inmates requiring medical care can happen there.

'It's shocking [to see] Australia letting their own vulnerable people down.'

'He's no longer a violent offender,' Tessa told us:

> [The] stress of being in jail is no good for his health. The environment is not calming [and Niles] is just treated like nothing, like nobody. Well, he's my son – he's somebody's – and [he has] a lot of support and a family who love him.

*** Names changed and some details removed to protect people's identities. Narrative based on a submission to the Royal Commission.**

10. Private sessions

Key points

- A private session is a confidential meeting between an individual and a Commissioner. The individual can have a support person attend, if they wish.
- A private session is not a hearing of the Royal Commission. It is a way for individuals to share their experiences in a supportive and less formal environment.
- Information that the Royal Commission receives in a private session informs our work and recommendations. It remains confidential after the inquiry ends.
- The Royal Commission has adapted the private sessions model to ensure it is accessible and inclusive.
- The private sessions process is trauma-informed.
- From March 2020 until June 2020, the Royal Commission suspended face-to-face private sessions due to the COVID-19 pandemic. Twelve private sessions were conducted by phone and videoconference during this period.

Introduction

The Royal Commission and the Australian community will not fully understand the nature and extent of violence against, and abuse, neglect and exploitation of, people with disability unless we hear directly from individuals with disability.

The terms of reference recognise this and state that we will be informed by individual experiences.[1] As outlined in Chapter 5, 'Our organisation', we are committed to ensuring that the voices, experiences and expertise of people with disability are at the centre of our work.

One of the ways we are doing this is by Commissioners listening to individuals in a private session, or meeting.

This chapter outlines:

- the nature and purpose of private sessions
- how private sessions are shaped by individual needs
- the process for conducting private sessions
- the legal protections for private sessions information.

Private sessions are a recent development

In the past, the main way that royal commissions gathered information from individuals was through formal hearings.

During the 2013–17 Royal Commission into Institutional Responses to Child Sexual Abuse, it became clear that many people wanted their experiences heard and acknowledged, but in a private and confidential setting that was less formal than a hearing. In response, the Australian Parliament amended the *Royal Commissions Act 1902* (Cth) in 2013 to allow for confidential meetings, or private sessions, between Commissioners and individuals.[2] These amendments were specific to the Royal Commission into Institutional Responses to Child Sexual Abuse.[3]

After a joint request by the Chair of this Royal Commission and the then Chair of the Royal Commission into Aged Care Quality and Safety, the Hon Richard Tracey AM RFD QC, on 13 September 2019 the *Royal Commissions Act* was amended to allow private sessions to occur at other royal commissions, if authorised by regulation.[4] The *Royal Commissions Regulations 2019* (Cth) authorise this Royal Commission to hold private sessions.[5] This acknowledges that traditional or more public settings may not be appropriate for some people who have experienced, or are aware of, violence against, or abuse, neglect or exploitation of, people with disability and wish to share these experiences with our inquiry.[6]

Nature and purpose of private sessions

A private session is a confidential meeting between an individual and a Commissioner, held at the individual's request. Individuals who attend are not witnesses and the information they provide in the private session is not evidence.[7]

An individual attending a private session can have a support person with them, if they choose to. The Commissioner holding the private session will determine how the session is conducted,[8] including deciding who should attend.

Many people who wish to provide information to the Royal Commission may not feel comfortable or may not be willing or able to share their experiences with us in a public way or through a submission. Others may be concerned about the confidentiality and use of their information after the Royal Commission ends. Private sessions are designed to address these concerns.

Private sessions help the Royal Commission to better understand the impacts of violence, abuse, neglect and exploitation on people with disability and their families and support people. They also provide people with an opportunity to propose recommendations to us about how to better prevent violence against, and abuse, neglect and exploitation of, people with disability.

The information provided in private sessions supplements the evidence we receive in public hearings and the information individuals provide in submissions, issues paper responses and community engagement activities. However, unlike at public hearings, a person attending a private session is not considered to be giving evidence to the Royal Commission.[9]

We acknowledge that it takes courage for people to come forward and share their experiences with us in a private session. Everyone who does so contributes to our work.

Responding to individual needs and requirements

People who wish to have a private session may have experienced trauma. Many people may prefer to tell the Royal Commission about their experiences through a private session because of the personal adjustments that can be put in place. The Royal Commission has carefully considered every aspect of the private sessions process to ensure our approach is supportive from end to end.

We work to ensure we can accommodate individual preferences as far as possible. Some of the ways we do this are by:

- giving people the opportunity to nominate who they would like to accompany them to their private session

- ensuring the length and format of the private session are appropriate, and allowing between one and two hours for people to share their experiences with us
- scheduling the private session in the most convenient location and at the most convenient time for the attendee
- giving people the opportunity to indicate a preference for the Commissioner who will conduct the private session, or any Commissioner they would like not to conduct the private session
- giving people the option to indicate a preference for the gender of any Commission staff who will sit in on the private session.

We carefully consider how to create the safest and most supportive environment for attendees. Every private session is held in a venue that has been selected because it is, to the greatest extent possible, accessible to people with disability, non-threatening and private. (The Royal Commission's Accessibility and Inclusion Strategy is discussed in Chapter 5.) Our private sessions are also designed to be trauma-informed.

To make sure that people are well supported to attend a private session, we arrange and pay for reasonable travel. This may include flights, accommodation, meal costs and taxi vouchers for both the private session attendee and their support person.

The Royal Commission plans to hold private sessions throughout Australia, including in rural and remote areas where practical. Where people do not wish to attend in person, we will consider holding a private session with them via phone or videoconference, if they specifically request this or indicate a willingness for it. The Royal Commission held 12 phone and videoconference private sessions during the COVID-19 pandemic, while face-to-face engagements were on hold.

It is important to us that people feel culturally, emotionally and physically safe at a private session. Where appropriate, we work closely with disability advocates, support services, First Nations service providers and community leaders, support people and family members in planning private sessions to ensure people are well supported before, during and after they attend.

We also have trained counsellors available to support people through every stage of the process, from registration to a debriefing afterwards (for more information, see Chapter 6, 'Support for people engaging with the Royal Commission').

The private sessions process

People can request a private session by calling the Royal Commission hotline, emailing our public enquiries mailbox, or registering using an online form. We will try to offer a private session to everyone who requests one, but that might not be possible if we have a significant number of requests. We will prioritise private sessions for people with disability, and those who are unable to share their experience in any other way because of confidentiality concerns.

When a person is offered a private session, a Royal Commission staff member completes a thorough intake process. Its main purpose is to ensure that the experience the person wants to share falls within the Royal Commission's terms of reference. However, it also helps us tailor the private session to suit individual needs as much as possible. During an intake call, we may also provide referrals to external counselling, advocacy or legal services if required.

When scheduling a private session, we will provide detailed information about all aspects of the venue and the private sessions process so attendees understand what to expect.

A week before the private session, a Royal Commission counsellor will make contact with the attendee to further explain the process, talk through any concerns they may have and make sure they feel adequately supported to attend. The counsellor will also be available in person on the day of the private session to offer support and will follow up with the attendee afterwards for feedback about their experience and to discuss any referrals to ongoing supports that may be required (see Chapter 6 for a list of funded services external to the Royal Commission).

As noted, anyone attending a private session can request to bring someone with them. This can be a friend, family member, advocate, counsellor, support person or disability support worker. If a person requires assistance to communicate, the person they bring is able to speak on their behalf in the session. If someone has particular accessibility requirements, the Royal Commission will assist, for example by organising an Auslan interpreter.

There is no strict format that a private session must follow. The attendee is able to share their experience in whatever way and format they feel most comfortable with. The Commissioner or Commission staff may ask questions to help guide the discussion.

Protection and use of private sessions information

People can speak freely during a private session because under the *Royal Commissions Act* this information must be treated confidentially.[10] The confidentiality provisions of the Act are discussed in detail in Chapter 4, 'Nature and powers of the Royal Commission'.

The information we obtain through private sessions helps us to understand recurrent themes and where we might focus our future work. We analyse information from private sessions for this purpose, after de-identifying it to maintain confidentiality. We do this by removing the person’s name and any features that could identify them.

Where appropriate, and only with the consent of the individual who attended, we may publish some of the information as narratives of people’s experiences. These will always be de-identified.[11] These narratives are intended to help the wider Australian community understand the personal experiences of people with disability. This is one way in which the Royal Commission aims to change public attitudes and to bring about the reforms needed to ensure that people with disability enjoy in practice the human rights they enjoy in theory.

Private sessions statistics

The Royal Commission held our first private sessions in February 2020 in Melbourne. We intend to carry out an extensive program of private sessions. Unfortunately, the number we have been able to hold to date has been significantly impacted by the COVID-19 pandemic. We temporarily suspended all private sessions from March 2020 until June 2020, to ensure the safety and wellbeing of the people engaging with us and of our staff.

As of 31 July 2020, we had conducted 17 private sessions. Of these, eight were attended by people with disability. The remainder were with family members of people with disability, support workers and a health professional.

Endnotes

1 *Letters Patent* (Cth), 4 April 2019 amended 13 September 2019, (l).
2 *Royal Commissions Amendment Act 2013* (Cth).
3 *Royal Commissions Amendment Act 2013* (Cth) s 6OB.
4 *Royal Commissions Act 1902* (Cth) pt 4, as amended by the *Royal Commissions Amendment (Private Sessions) Act 2019* (Cth).
5 *Royal Commissions Act 1902* (Cth) pt 4, as amended by the *Royal Commissions Amendment (Private Sessions) Act 2019* (Cth), and the *Royal Commissions Regulations 2019* (Cth) reg 7.
6 *Letters Patent* (Cth), 4 April 2019 amended 13 September 2019, (k).
7 *Royal Commissions Act 1902* (Cth) s 6OC(1).
8 Having regard to any directions given by the Chair of the Royal Commission. *Royal Commissions Act 1902* (Cth) s6OB(4).
9 *Royal Commissions Act 1902* (Cth) s6OC(1)(a).
10 *Royal Commissions Act 1902* (Cth) s 6OH.
11 *Royal Commissions Act 1902* (Cth) s 6OJ.

Harry*

Harry was born blind and also deaf in one ear. His combined disabilities mean he has always had difficulty with spatial concepts and sense of direction. Now in his forties and profoundly deaf, he lives in a group home. Harry said in his submission that he wonders whether he could be living a more independent life if his education had provided the living skills he needs.

Harry told us that as a kid he was always getting in trouble. In kindergarten, teachers would punish him in humiliating ways. Once his teacher made him wear his socks and shoes on his hands instead of his feet because he did something 'silly'.

Harry attended a special school for the blind where a 'lot of bad stuff went down and I was quite traumatised and I was humiliated and made to feel insignificant'.

Harry told us his lack of spatial awareness wasn't diagnosed until he was about to leave school, but it got him in plenty of trouble while he was there. When he got lost on the way to class, lost his footing or forgot something, teachers would tell him he was stupid. They would punish him by humiliating him – smacking him, not letting him join in activities with the other kids or just making him feel 'really really low'.

Harry saw other kids with disability being humiliated and abused too. He remembers one boy, who couldn't talk and could barely move, who would wet his pants. 'I'd hear the teacher smack him,' Harry recalled, 'and the scream, I can still remember his scream … a really tortured scream. A primal scream.'

'I could go on,' said Harry. 'I could give many examples of things that happened … You know some of the teachers shouldn't have been teachers.'

When Harry was about 10 years old he started having regular one-on-one musical therapy sessions. The music teacher, Susan, told him that the sessions would calm him down so that he'd behave better in class. During these sessions Harry wasn't allowed to talk and had to do everything by touch and feel. Susan called these sessions their 'special time'. She would put on some music and dance or just move about, and he was supposed to follow her movements. Harry felt really close to Susan, who he thought was his friend.

One time, Susan put on a slow instrumental piece and got Harry to lie on top of her with his arms stretched out in front of him. He told us:

> It was very intimate … I was only [10] at the time. I didn't have any idea what sex was. I was really uncomfortable but I didn't know how to say it. I thought it was normal. I thought I was silly for feeling uncomfortable.

While Harry felt uncomfortable when these things were happening, it didn't immediately seem to have an impact on him. Then, in his twenties, he started having dreams and flashbacks and became emotional and upset.

One day, by chance, Harry ran into Susan in a shop and they exchanged contact details. After a couple of meetings, Harry tried to talk with Susan about what had happened all those years ago:

> All my emotions came out and everything was mixed up in my head … I asked what did it all mean? Why did all these things happen? What was the purpose of our therapy sessions?

Susan got angry and refused to discuss it. 'If you have a problem with it, go see a counsellor!' Harry recalled her saying. She promptly cut off all contact: 'I just didn't know where to go, didn't know what to do, and I needed some support. She just turned her back on me.'

Remembering all this, Harry said, 'Yeah, I survived. But that's not the same as being unscathed, you know what I mean?'

*** Names changed and some details removed to protect people's identities. Narrative based on a submission to the Royal Commission.**

11. Research and policy

Key points

- The Royal Commission’s research agenda and policy work are designed to examine in depth the violence, abuse, neglect and exploitation experienced by people with disability and inform our recommendations.
- The research agenda:
    - builds an evidence base of applied research
    - guides the process of developing our recommendations
    - delivers high quality peer-reviewed research reports from leading researchers.
- The Royal Commission’s policy work gathers information and evidence on systemic issues related to our terms of reference from a range of sources including submissions, public hearings, private sessions, community engagements and research. We also seek input through workshops as well as by inviting responses to issues papers that ask questions about a particular topic.
- All of these sources of information and evidence will inform and contribute to developing recommendations for lasting change.

Introduction

The Royal Commission's research agenda and policy work are part of our in-depth examination of violence against, and abuse, neglect and exploitation of, people with disability. The work informs this interim report and will inform the content and recommendations of our final report.

This chapter outlines:

- the purpose of our research and policy work
- our research agenda
- our policy work, and what informs it.

Our approach to our policy and research work

People with disability are at the centre of our work

From its beginnings in the 1970s and 1980s, the disability rights movement has been led by people with disability. Encapsulated in the principle of 'nothing about us without us', the movement calls for the full participation of people with disability in the development and implementation of relevant law, policy and practice.[1] The disability rights movement played a key role in drafting the United Nations *Convention on the Rights of Persons with Disabilities* (*CRPD*),[2] with people with disability and international disability rights organisations participating directly in its drafting.[3]

Our research and policy work applies a theoretical framework that places the knowledge and experiences of people with disability at the forefront of our analysis. This framework includes human rights and life course approaches, disability models and theories, and intersectionality, which seeks to understand multi-layered experiences of discrimination. We outline this in detail in Chapter 16, 'Our theoretical approaches'.

Our research and policy work also draws on the personal experiences that people share with the Royal Commission through submissions, public hearings, community engagements and private sessions. We are committed to ensuring that people with disability engage with us in the way that best suits them.

Our research agenda

Our research agenda has two main aims.

First, it will build an evidence base of applied research to support all areas of the Royal Commission's work. In particular, our research agenda aims to develop a solid evidence base to inform the recommendations we make in our final report. The research agenda includes an in-depth analysis of past inquiries and reports that are relevant to our terms of reference which will identify whether the recommendations in these inquiries have been implemented and, if not, to examine why.

Second, the research agenda will contribute a legacy to the research community. We aim to fill gaps in the evidence base for advocates, governments, service providers, other organisations and researchers to use after the Royal Commission has completed its inquiry. Our research projects are conducted by leading researchers, and reports are independently reviewed by other experts in the field. This high quality, peer-reviewed research is published on our website so reports are publicly available as our inquiry progresses and after it has finished.[4]

What we have done so far

The first stage of our research agenda established the background to our inquiry and examined the history of disability in Australia from legal, social and cultural perspectives. This research has contributed to the development of this report and will be published on our website. These projects include:

A historical account of the sociocultural context of disability in Australia

This internal project, with contribution from Professor Richard Bruggemann and Colleen Johnson, is a historical account of disability in Australia. The report briefly covers the history of First Nations people with disability, the colonial period, changes to social and political trends as they relate to people with disability through the 19th, 20th and 21st centuries, and contributions made by the disability rights movement to identifying maltreatment and promoting change.

A revolutionary act

This essay was written by journalist Joel Deane and co-author Leah van Poppel. It provides a narrative of events leading to the establishment of the Royal Commission. It starts with the 1973 launch of the Australian Assistance Plan[5] and ends at calls for a Royal Commission. It covers a range of issues involving people with disability, including employment, education, forced sterilisation, violence and domestic violence, indefinite detention, and the placement of young people with disability in nursing homes.

An exploration of the vocabulary used by people living with disability

It is critical that our research includes the voices of people with disability. We commissioned social researchers JFA Purple Orange to study the language people with disability use to describe violence, abuse, neglect and exploitation. The project explored language around safety and self-determination through 14 focus groups with people with disability, their families and supporters. This project helps us better understand the experiences of people with disability as they engage with the Royal Commission at public hearings, and through community forums, submissions, private sessions, and responses to issues papers.

A related project, written by an expert on First Nations people with disability, Dr Scott Avery, examined ways in which First Nations people talk about violence and abuse, as well as empowerment, sovereignty and self-determination. Chapter 18, ‘First Nations people with disability’, draws on findings from this research to discuss the concept of disability within First Nations communities.

Hierarchies of power: Disability theories and models and their implications for violence against, and abuse, neglect, and exploitation of, people with disability

This paper was written by Royal Commission social researcher Professor Shane Clifton. It discusses debates among disability theorists and activists about how to understand disability, and how these understandings have influenced policy development and practice. Chapter 16 explains the theoretical frameworks we apply to our work, including the disability models and theories examined in this project.

Nature and extent of violence, abuse, neglect and exploitation against people with disability in Australia

This report provides an analysis of the currently available quantitative data on the number of people with disability in Australia, and the prevalence of violence against, and abuse, neglect and exploitation of, people with disability in Australia. The findings of this report, developed by the Centre of Research Excellence in Disability and Health, are discussed in detail in Chapter 15, ‘Nature and extent of violence against, and abuse, neglect and exploitation of, people with disability’.

Convention on the Rights of Persons with Disabilities: Shining a light on social transformation

This project provides an explanation of the international human rights context in which the Royal Commission operates, particularly as it relates to the *CRPD*. The report covers the development and negotiation of the *CRPD* as well as the significance of its final content. The report covers themes such as inequality, segregation and discrimination, shifts in understanding disability, the process of developing the *CRPD* and the interpretation of human rights. It was written by Rosemary Kayess (University of New South Wales) and Therese Sands (Independent Consultant, Human Rights and Disability).

The United Nations Convention on the Rights of Persons with Disabilities: An assessment of Australia’s level of compliance

Emeritus Professor Ron McCallum AO, Senior Advisor to the Royal Commission, has prepared a detailed research report examining the extent to which Australia has and has not implemented the *CRPD*. The research report takes into account the General comments made by the Committee on the Rights of Persons with Disabilities and the Committee’s 2013 and 2019 concluding observations on Australia’s implementation of the *CRPD*, following Australia’s reporting to and interactive dialogue with the Committee.

Past reports and inquiries

Our terms of reference direct us to consider the findings and recommendations of relevant past reports and inquiries.[6] A large research project is underway to do this. We are using a robust methodology to identify the relevant reports and inquire into whether their recommendations have been implemented by the agencies and entities at which they were directed. This project will also examine the barriers to, and facilitators of, implementing recommendations.

We have identified more than 240 reports and inquiries on a range of topics that have been published over the past 25 years. These have been authored by academics, disability organisations, non-government organisations, the United Nations, and the Australian Government and state and territory governments.

Appendix B lists the more than 240 reports relevant to our inquiry.

We used the following criteria to identify the most relevant inquiries and reports:

- the report contained findings and recommendations that addressed violence against, and abuse, neglect and exploitation of, people with disability
- the report addressed specific aims and articles of the *CRPD* or other international human rights instruments
- the report was published under the authority of a statutory or non-statutory body at state/territory, federal or international level
- the report was published during or after 1995.

We were also interested in reports that:

- included the participation of people with disability or their representative organisations
- applied an intersectional approach and/or recognised diversity among people with disability. This included reports that had a specific focus on examining issues for First Nations people with disability. We are also interested in reports that had a focus on people from culturally and linguistic diverse backgrounds, women, children and young people, older people, rural communities and the LGBTIQ+ community.

We are now analysing the most relevant reports and their recommendations in detail. We will examine, as far as possible, whether recommendations:

- have been implemented and whether the objectives of the recommendations have been met
- have not been implemented and the reasons for this.

If necessary, we will also use the Royal Commission’s coercive powers as appropriate to obtain information and/or documents to help with this analysis. (See Chapter 4, ‘Nature and powers of the Royal Commission’, for more details about those coercive powers.) Information and/or documents obtained through exercise of our coercive powers will be analysed together with information we receive via submissions, our research, and publicly available information on the implementation of recommendations from past reports and inquiries as well as evidence from public hearings. This analysis will contribute to and inform our public hearings and our policy and research work. The project will also be an important source of information to inform how we develop recommendations that are practical, implementable and lead to lasting change.

Legislative and policy frameworks affecting people with disability

We have examined the legislative and policy frameworks that affect people with disability in Australia across a number of projects. They cover legislation and policy across state, territory, and federal jurisdictions. The projects are:

- an outline of the constitutional powers that underpin the Australian Government's legislative and policy agenda for people with disability. The report, produced by Professor John Williams (University of Adelaide), Associate Professor Matthew Stubbs (University of Adelaide) and Adam Webster (Oxford University), examines the treatment of people with disability under the *Australian Constitution* and federal laws over three periods of social change: at the time of drafting the Constitution, after the Second World War, and today.
- a detailed overview of the legislative frameworks affecting people with disability. It covers state, territory and federal laws that apply specifically to people with disability, and the general application of laws that affect people with disability. This work was produced by the Australian Government Solicitor. A related project examines laws relating to the education of people with disability. This project was undertaken by legal researcher Sam Murray.
- an outline of the development of Australian policy frameworks affecting people with disability over the past 120 years. This was developed internally by the Royal Commission.

Our policy work

The purpose of our policy work is to understand the systemic factors that contribute to violence, abuse, neglect and exploitation experienced by people with disability and develop recommendations that address systemic issues and lead to lasting change.

This section outlines the workshops held and issues papers the Royal Commission has published so far. They cover a range of policy issues relevant to our terms of reference.

The Royal Commission gathers information on issues relevant to our terms of reference and identifies potential recommendations from what we hear through submissions, responses to issues papers, workshops, public hearings, private sessions, community forums, engagement and research.

We discuss what we are learning from all these sources of information in Chapter 17, ‘Emerging themes and key issues’ and Chapter 18.

Workshops

Early in our inquiry, we held nine workshops with stakeholders to discuss particular policy issues related to our terms of reference. Participants at the workshops identified issues and shared ideas and information on specific topics affecting people with disability.

Advocacy workshop

On 18 June 2019, the Royal Commission held a workshop in Melbourne, Victoria with disability advocates from across Australia. At this workshop, Commissioners acknowledged that the Royal Commission was the result of many decades of advocacy by people with disability and their supporters. Participants reiterated the right of people with disability to live self-determined lives, participating in every aspect of life and in every sector of the Australian community, free from violence, abuse, neglect and exploitation. Participants acknowledged the relationship between discrimination, racism, poverty, gender, trauma and other issues that interact in a person’s life.

The key issues discussed included:

- the experiences of people with disability in institutional settings
- the particular experiences of people with disability who have been denied capacity under current Australian law in circumstances where Article 12 of the *CRPD* requires States Parties to ensure that people receive the necessary support to express their own will and preference[7]
- the experiences of people with disability interacting with police and the justice system.

Legal workshops

The Royal Commission held workshops with legal practitioners and advocates with disability law expertise on 1 July 2019 in Sydney, New South Wales; 3 July 2019 in Brisbane, Queensland; and 9 July 2019 in Melbourne, Victoria. Participants highlighted that when people with disability experience violence, abuse, neglect or exploitation in one area of life, it was likely to have significant flow-on effects in others.

The discussion at the workshop focused on:

- legal issues and barriers for people with disability, focusing on homes and living, education and learning, economic participation, and justice
- concerns about the National Disability Insurance Scheme (NDIS)
- the importance of law reform in relation to disability rights and disability services.

Disability service providers workshop

The Royal Commission held a workshop with a small group of disability service providers on 18 July 2019 in Melbourne, Victoria. Participants discussed the interface between different service systems, such as health, family services and justice, and the role of the NDIS. A central issue discussed was the impact of the NDIS on service delivery. Participants also raised issues related to living circumstances and employment, such as the role of Australian Disability Enterprises.

First Nations people and communities workshops

The Royal Commission held workshops with First Nations leaders on 6 August 2019 in Sydney, New South Wales and 15 August 2019 in Darwin, Northern Territory. The purpose of these workshops was to give community leaders, Elders and key advocates the opportunity to talk to the Royal Commission about major issues facing First Nations people with disability. Participants spoke about their experiences across a number of areas, including ableism, racism, discrimination and racial stereotyping.

Participants raised concerns about a range of issues including:

- institutional racism within the health system, and the lack of services in remote settings for First Nations people with disability
- education for First Nations children with disability, including concerns that the needs of First Nations children with cognitive impairments are not met throughout school due to the misperception that certain behaviours are a disciplinary matter.

Participants in both workshops emphasised the critical importance of member-led First Nations organisations leading services and support to First Nations people with disability at the local and regional level.

Justice workshop

The Royal Commission held a workshop on people with disability in the justice system on 2 September 2019 in Melbourne, Victoria. The workshop explored policing practices, as well as arrest, charge, prosecution, legal and court processes. The workshop was attended by advocacy groups, academics, public advocates and guardians, and representatives from the legal assistance sector, including First Nations legal services. Participants raised the barriers and challenges experienced by people with disability in the criminal justice system, including:

- legal capacity of people with disability
- indefinite detention of people with disability
- barriers to the complaints process within the criminal justice system.

Education and learning workshop

The Royal Commission held a workshop on education and learning on 3 October 2019 in Melbourne, Victoria. Participants included representatives from universities, legal assistance sector and advocacy groups. Participants discussed:

- strategies that have been effective in realising the right of people with disability to education
- barriers to implementing inclusive education in Australia
- attitudes and culture in education, teacher training, funding and data collection
- whether Australian teaching standards are consistent with the *CRPD*.

Issues papers

The Royal Commission publishes issues papers so we can hear from people with disability and others about important topics related to our terms of reference.

As at 31 July 2020 the Royal Commission has published nine issues papers.

We have received many very detailed, thoughtful and well researched responses to issues papers that provide invaluable information for our inquiry. These have been provided by people with disability, their families, advocacy groups, peak bodies, academics and other researchers, government agencies, statutory bodies and practitioners (including teachers, medical professionals and legal professionals). The Royal Commission reads and gives careful consideration to every response we receive.

The Royal Commission will publish an overview of the responses to each issues paper that summarises what we have been told. We also publish responses to issues papers on our website.[8]

As at 31 July 2020, we had received 296 responses to issues papers.

Education and learning (30 October 2019)

The *Education and learning issues paper* outlines the Royal Commission's preliminary understanding of key issues and barriers experienced by students with disability in realising their right to a quality education, including through inclusive education. It asks people and organisations for information relating to our terms of reference in the context of education and learning. We have received 53 responses.

Group homes (28 November 2019)

The *Group homes issues paper* looks at 'group homes', which it defines as a form of accommodation where services and supports are provided to four to six long-term residents with disability. The issues paper discusses group homes in the context of deinstitutionalisation in Australia. It also notes research which suggests that segregated environments, such as group homes, may increase the risk of violence, abuse, neglect and exploitation for people with disability. This issues paper asks about the experiences of people with disability in group homes, including quality of life, restrictive practices, barriers to reporting and staffing issues. We have received 36 responses.

Health care for people with cognitive disability (16 December 2019)

The *Health care for people with cognitive disability issues paper* seeks information on the experiences of people with cognitive disability in accessing health care. The issues paper discusses barriers that people with cognitive disability face in accessing health care, which may result in poorer health outcomes. It asks about experiences accessing health care, including barriers, the NDIS and experiences of violence, abuse, neglect and exploitation. We have received 42 responses.

Criminal justice system (14 January 2020)

The *Criminal justice system issues paper* outlines the Royal Commission's preliminary understanding of key issues and barriers experienced by people with disability when they engage with the criminal justice system, whether as victims of or witnesses to crimes, or as offenders. The issues paper highlights that people with disability, particularly young people and First Nations people with disability, are at heightened risk of violence, abuse, neglect and exploitation and are also over represented in the criminal justice system. It asks about the problems people with disability face when interacting with the different agencies that make up the criminal justice system. We have received 46 responses.

Emergency planning and response (15 April 2020)

The *Emergency planning and response issues paper* calls for information on the experiences of people with disability during emergencies, such as the 2019–2020 bushfire season and the COVID-19 pandemic. It invites information on how Australian governments include people with disability in preparing for and responding to emergencies and how this could be improved. We have received 60 responses.

Rights and attitudes (29 April 2020)

The *Rights and attitudes issues paper* asks about levels of awareness and recognition of the rights of people with disability, as well as how well advocacy works to promote and defend these rights. The issues paper also asks for information on how attitudes – including stigma, ableism and paternalism – affect people with disability. We have received 42 responses.

Employment (12 May 2020)

The *Employment issues paper* relates to the experiences of people with disability receiving an income, including through paid work, independent contracting, self-employment and apprenticeships, as well as in segregated employment settings, such as Australian Disability Enterprises. It asks for information on the barriers people with disability face to employment that may prevent financial independence and other benefits associated with work, including dignity, a sense of purpose and social connectedness. We have received 10 responses.

Restrictive Practices (26 May 2020)

The *Restrictive practices issues paper* examines the use and impact of seclusion and restraints on people with disability in all areas of life and in various settings. The paper outlines current government approaches to restrictive practices, including in health systems, disability services, education settings and under guardianship arrangements. It asks for information about how restrictive practices can be avoided, alternative measures and strategies that could be used and how laws, policies and practices could be improved. We have received 7 responses.

First Nations people (9 June 2020)

The experience of First Nations people with disability in Australia issues paper outlines the Royal Commission's preliminary understanding of some of the key issues and barriers affecting First Nations people with disability. It asks First Nations people with disability and those who advocate and care for them to identify areas of concern, including what can be done to better prevent them from experiencing violence, abuse, neglect and exploitation. We are particularly interested in government and community led solutions that are working well and could be better supported. The Royal Commission is looking forward to receiving responses to this important issues paper.

Endnotes

1 James I Charlton, *Nothing about us without us: Disability oppression and empowerment*, University of California Press, 2000, p 3.
2 *Convention on the Rights of Persons with Disabilities*, opened for signature 30 March 2007, 999 UNTS 3 (entered into force 3 May 2008).
3 Arlene Kanter, *The development of disability rights under international law: From charity to human rights*, Routledge, 2015, p 40.
4 'Research program', *Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability*. <https://disability.royalcommission.gov.au/policy-and-research/research-program>
5 Social Welfare Commission, *Report on the Australian Assistance Plan*, Parliamentary Paper, No. 96, 1976.
6 *Letters Patent* (Cth), 4th April 2019 amended 13 September 2019, (j).
7 *Convention on the Rights of Persons with Disabilities*, opened for signature 30 March 2007, 999 UNTS 3 (entered into force 3 May 2008) art 12.
8 'Issues papers', *Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability*. <https://disability.royalcommission.gov.au/policy-and-research/issues-papers> Note that the Royal Commission may publish a response to an issues paper where a person has indicated that they consent to publication, and where the Royal Commission considers it appropriate to do so. However, the Royal Commission is not required to publish information it receives and, when we do, we do so in line with our legal obligations. This means that in some cases we may need to redact parts of documents, or may not publish documents even if a person would like us to do so.

Hugh*

Hugh has a university degree and experience in IT. He estimates that during the past five years he has applied for approximately 14,300 jobs. Hugh is sure he's not 'an isolated example of someone with a disability unable to secure work'.

Hugh has an acquired brain injury and autism spectrum disorder and as a result he requires a flexible working environment. 'I am upfront about the nature of my disability and the type of reasonable adjustments that I require,' he said in his submission.

These adjustments include working in a space where he's not surrounded and distracted by other workers and having control 'over the intensity of the workload'. In other words 'part-time, flexible hours' working from home would be ideal. Hugh is adamant that 'there is no reason I cannot perform IT work remotely'.

Even though he has adapted his CV and cover letters following advice from various employment service providers, Hugh rarely gets to the next stage. When he has been interviewed he has felt 'intimidated by a management structure that refuses to acknowledge' his flexibility requirements.

Being unable to find employment means he has been 'forced to rely on the disability support pension for many years ... despite my willingness to engage in employment'. Needless to say, 'the impact of applying for so many jobs over such a lengthy timeframe has been demoralising'.

Hugh has had five Disability Employment Services (DES) providers over the past five years, and he questions their role. He said he has found them 'inadequate and ineffective, they have not helped me at all'. He told us he believes they are failing people with disability, particularly people with acquired brain injuries and autism. He would like to see them work more proactively to influence employers to understand the needs of people with specific disabilities.

Hugh has complained to the Australian Human Rights Commission, DES providers, a government department and a minister. He is unsatisfied with the response – or lack of response.

Not being able to work means Hugh is 'confined to social welfare ... simply unable to live the sort of quality of life ... that my studies should have afforded me'.

He said he believes that businesses should be strongly incentivised to offer employment to people with disability in an environment where 'they feel comfortable – such as their own home – on a flexible basis'.

*** Name changed and some details removed to protect people's identities. Narrative based on a submission to the Royal Commission.**

Part C: Our work to date

Part C of the interim report provides an overview of the Royal Commission's first three public hearings, which focussed on inclusive education in Queensland, group homes, and health care for people with cognitive disability. The chapters summarise the key themes that emerged from the hearings, and outline the areas for future inquiry that arose.

Part C also examines the data available on people with disability in Australia, and identifies the gaps in that data.

Chapter 12, 'Public hearing 2: Inclusive education in Queensland – preliminary inquiry' summarises the first of our public hearings to examine violence against, and abuse, neglect and exploitation of, people with disability in educational settings. Education was selected as the first topic for public hearing because of its importance to the life journey of people with disability and in recognition of the pervasive and significant effect that adverse experiences can have on a person's life.

Chapter 13, 'Public hearing 3: The experience of living in a group home for people with disability' summarises our public hearing into the experiences of living in a group home for people with disability. The hearing examined, in particular, whether living in a group home created particular risks of violence, abuse, neglect or exploitation for people with disability.

Chapter 14, 'Public hearing 4: Health care and services for people with cognitive disability' summarises our first public hearing into health issues for people with disability. The purpose of the hearing was to examine the health care and services provided to people with cognitive disability in Australia and to determine whether this group of people is subjected to systemic neglect.

Chapter 15, 'Nature and extent of violence against, and abuse, neglect and exploitation of, people with disability' describes the importance of high quality data and the work the Royal Commission has done to uncover what data is available and what remains unknown. There is good data on the number of people with disability in Australia, but little available on the violence, abuse, neglect and exploitation experienced, particularly by some groups such as First Nations people with disability, people with disability from culturally and linguistically diverse communities, and people with disability living in closed or segregated environments. The chapter outlines the Royal Commission's strategy to address these data gaps.

Content warnings

Please be aware that this report contains information that may be distressing to readers.

It includes accounts of violence against, and abuse, neglect and exploitation of, people with disability and references to suicide and self-harming behaviours.

In some first-hand accounts of violence, abuse, neglect and exploitation, people have told us of abusive or offensive language they have experienced or witnessed. As a result, some direct quotes in the report contain language that may be offensive to some people.

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

If you need support to deal with difficult feelings after reading this report, there are free services available to help you. Information about these services can be found at the beginning of this report (see page vi) and in Chapter 6, ‘Support for people engaging with the Royal Commission’.

12. Public hearing 2: Inclusive education in Queensland – preliminary inquiry

Key points

- In Public hearing 2, the Royal Commission conducted a preliminary inquiry into the issue of education for people with disability.
- Education was selected as the topic because of its fundamental importance to the lives of people with disability as a key enabler of access to other rights, including workforce and community participation.
- The hearing was held in Queensland because the state has recently introduced an inclusive education policy, developed after an independent review of the education of students with disability in state schools.
- The Royal Commission heard evidence from 14 witnesses, including parents of students with disability, representatives from advocacy organisations, academic experts, representatives from the Queensland Department of Education and the president of the Queensland Teachers' Union.
- From Public hearing 2 evidence, and from submissions and other information received and obtained, the Royal Commission has identified several areas for further inquiry, including:
    - gatekeeping
    - mistreatment by school staff and other students, including bullying
    - the use of restrictive practices
    - a lack of adjustments, supports and individualised planning
    - low expectations of students with disability
    - misuse of disciplinary measures, including suspensions and exclusions
    - poor communication and complaint handling
    - funding complexities
    - insufficient teacher training for students with disability
    - the adequacy of data collection
    - the challenges faced by students with disability from First Nations and culturally and linguistically diverse communities.
- The Royal Commission will also continue to examine the issue of inclusive education.

Introduction

The Royal Commission held Public hearing 2: Inclusive education in Queensland – preliminary inquiry, from 4 to 7 November 2019 at the Townsville Entertainment and Convention Centre in Queensland. The main purpose of the hearing was to undertake a preliminary examination of the systemic issues, challenges and barriers that can prevent students with disability from obtaining a safe, inclusive and high quality education.

The themes and issues examined at this public hearing have also been raised with the Royal Commission through submissions, responses to issues papers, research and community engagement. Chapter 17, 'Emerging themes and key issues' provides a more detailed discussion of the emerging themes and key issues raised to date.

Public hearing 2 was the first hearing of the Royal Commission in which evidence was taken. Education was selected as the topic because of its importance to the lives of people with disability and in recognition of the pervasive and significant effect that adverse educational experiences can have on a person's life.

The Royal Commission heard from parents of students with disability about their experiences of the education system in Queensland and other states and territories at public and private schools. We also heard evidence from two representatives of disability advocacy organisations who spoke to common themes that have emerged from their work with students with disability and parents and support persons of students with disability, again at both public and private schools.[1]

Before and since the hearing we have received a significant number of submissions about education, including from students with disability, parents and support people of students with disability and advocacy groups. These submissions have poignantly demonstrated the impact that violence against, and abuse, neglect and exploitation of, students with disability can have.

Under international law, the right to education is a key human right that belongs to everyone.[2] The right to education is often described as a 'multiplier' right, as it can enable access to and increase the enjoyment of other rights.[3] These may include enabling people to obtain work, enjoy a high standard of health and participate in public life.

While learning is a lifelong process, the United Nations *Convention on the Rights of the Child* (*CRC*) emphasises that education is particularly important for children to develop and reach their full potential.[4] To fulfil the rights of all children, the United Nations Committee on the Rights of the Child states that education should be 'child-centred, child-friendly and empowering' and should give children knowledge and appreciation of their human rights.[5]

Article 24 of the *Convention on the Rights of Persons with Disabilities* (*CRPD*) provides that States Parties such as Australia recognise the right of people with disability to education and says that to realise that right 'without discrimination and on the basis of equal opportunity', States Parties shall 'ensure an inclusive education system at all levels and lifelong learning directed to:

(a) The full development of human potential and sense of dignity and self-worth, and the strengthening of respect for human rights, fundamental freedoms and human diversity;

(b) The development by persons with disabilities of their personality, talents and creativity, as well as their mental and physical abilities, to their fullest potential; and

(c) Enabling persons with disabilities to participate effectively in a free society.'[6]

Article 24 provides that States Parties shall ensure that people with disability are not excluded from the general education system on the basis of disability and can access an inclusive, quality and free primary and secondary education on an equal basis with others in the communities in which they live.[7] This includes ensuring the provision of 'reasonable accommodation'[8] and supports.[9]

As well as numerous submissions about the education of students with disability, the Royal Commission received many detailed responses to our *Education and learning issues paper*, published in October 2019. Many of these responses address the interpretation of Article 24 of the *CRPD*, taking into account the views stated by the United Nations Committee on the Rights of Persons with Disabilities (CRPD Committee) in General comment No. 4 on the meaning of the right to inclusive education in Article 24.[10]

General comment No. 4 notes that some students with disability are educated in 'separate environments designed or used to respond to a particular or various impairments, in isolation from students without disabilities'.[11] The CRPD Committee refers to this as 'segregation'. In Australia, schools, classes or units for students with disability are often called 'special' schools, classes or units. The CRPD Committee in General comment No. 4 states that Article 24 is 'not compatible with sustaining two systems of education: mainstream and special/segregated education systems'.[12] We use this terminology to describe the two systems of education.

The opinions expressed about the proper interpretation of Article 24 in submissions and responses to the issues paper have varied. Some argue that Article 24 must be broadly interpreted to require, for example, States Parties to phase out special, or segregated, schools.[13] Others, including the Australian Government,[14] contend that retaining state-run special/segregated schools is compatible with the requirements of Article 24. On this approach, the broad interpretation of Article 24 endorsed by the CRPD Committee is not conclusive.

It can be seen that the interpretation of Article 24 of the *CRPD* is by no means a straightforward matter. The Royal Commission will consider the various interpretations of Article 24 in detail in our work. In doing so we will bear in mind the issues for inquiry that are identified in our terms of reference.

We will pay attention to the fact that, as yet, no Australian jurisdiction has expressly recognised that all students with disability have a right, in law, to inclusive education. We will consider what long-term impact this can have on the social development and life course of people with disability. We will also consider the concerns raised by the CRPD Committee about Australia's progress in ensuring an inclusive education system.[15]

The Royal Commission has published a detailed report on Public hearing 2, which is available on our website. This chapter refers to evidence heard in Public hearing 2 but does not cover every issue raised in evidence.

As noted above, this chapter also refers to some submissions and responses to the issues paper that we received outside the hearing. It does this in the context of a discussion about the drivers of violence against, and abuse, neglect and exploitation of, students with disability and in identifying further areas for our inquiry.

Witnesses

The Royal Commission heard evidence from 14 witnesses at Public hearing 2. They included parents of students with disability, representatives from advocacy organisations, academic experts, the president of the Queensland Teachers' Union and staff of the Queensland Department of Education, including heads of inclusive education and principals at Queensland state schools and the Assistant Director-General State Schools – Disability and Inclusion Branch.

The Royal Commission particularly wishes to acknowledge that the two parents of students with disability were the first witnesses in a public hearing of this Royal Commission to share their personal experiences of how their children have been treated in public and private schools.

One parent of a student with disability spoke of the different experiences of her 13-year-old daughter, who has Down syndrome and vision impairment, in several 'mainstream' primary schools and of her transition to a mainstream high school.[16]

The witness told us that at one mainstream primary school her daughter was frequently removed from the classroom and 'babysat' in that school's special education unit and discouraged from participating in extracurricular activities.[17] She spoke of the positive changes in her daughter's education experience after moving to a different mainstream primary school. She told us of the importance of that school's supportive leadership, positive approach and enthusiasm in helping her daughter to access the curriculum and participate in the school's programs and peer groups.[18]

Another witness gave evidence about her experiences and those of her five children with disability in Queensland schools. She described a poor understanding of disability at two mainstream Queensland private schools. This included a failure of the schools to provide adjustments to support her children's learning and that the capacity to resolve complaints and problems in schools was limited.[19]

Inclusive education and initiatives in Queensland

The Royal Commission selected the Queensland system for Public hearing 2 because the education of students with disability within its state schools had been the subject of an independent review. The *Review of education for students with disability in Queensland state schools* (Queensland disability review) was commissioned by the Queensland Department of Education and Training, and published in 2017.[20]

The review made recommendations on a wide range of issues, including cultural change, workforce capability and changes to policy and procedure. Following the review, the Queensland Department of Education implemented an inclusive education policy.[21]

That policy states that:

> Inclusive education means that students can access and fully participate in learning, alongside their similar-aged peers, supported by reasonable adjustments and teaching strategies tailored to meet their individual needs. Inclusion is embedded in all aspects of school life, and is supported by culture, policies and every day practices.[22]

This definition of inclusive education is consistent with the explanation given by Professor Suzanne Carrington, Professor and Associate Dean of Research at Queensland's University of Technology, an academic expert in the field of education. She stated that inclusive education was about supporting the diversity of learners and achieving equity so that children had the best opportunity to be successful in both learning and social participation.[23] Professor Carrington also said that, 'inclusive education is based on equity, which is about ensuring that all children have what they need to be successful in their learning.'[24] Professor Carrington referred to the CRPD Committee's General comment No. 4 on Article 24 of the *CRPD*, and observed that:

> the right to inclusive education encompasses a transformation in culture, policy and teaching practice in all educational environments to accommodate the different requirements and identities of individual students, together with a commitment to remove the barriers that impede that possibility.[25]

Importantly, Queensland's Inclusive Education Policy observes that:

> Inclusive education differs from the following approaches and practices in significant ways:
>
> Integration – students are placed in schools or educational settings with their similar-aged peers but adjustments are not made to meet their individual needs. This limits their ability to fully access or participate in learning. Integration is not necessarily a step towards inclusion.
>
> Segregation – students learn in separate environments, designed or used to respond to their particular needs or impairment, in isolation from other students.
>
> Exclusion – students are unable to access any form of education.[26]

The Queensland Government Inclusive Education Policy, which aims to promote inclusiveness for all students, is guided by nine principles adapted from the United Nations' nine core features for inclusive education:[27]

- a system-wide approach
- committed leaders
- whole of school
- collaboration with students, families and the community
- respecting and valuing diversity
- confident, skilled and capable workforce
- accessible learning environments
- effective transitions
- monitoring and evaluation.

The Queensland Inclusive Education Policy contains a commitment that children and young people across Queensland of all identities and abilities can:[28]

- attend their local state school and education centre and be welcomed
- access and participate in a high-quality education and fully engage in the curriculum alongside similar aged peers
- learn in a safe and supportive environment, free from bullying, discrimination or harassment
- achieve academically and socially with reasonable adjustments and supports tailored to meet their learning needs.

The policy states that the Department of Education will continue to offer parents the choice of enrolling their child, if they meet set criteria, in individualised programs, including through special schools and academies.[29]

Public hearing 2 was the start of the Royal Commission's examination of the implementation and impact of the Queensland disability review recommendations and the operation of the state's Inclusive Education Policy. It also provided an opportunity for us to begin to understand the complexity surrounding parental choice.[30]

The Queensland Department of Education acknowledges that its work in inclusive education is still in progress. Assistant Director-General State Schools – Disability and Inclusion Branch, Ms Deborah Dunstone, observed that:

> We acknowledge that education is one of the most important foundations to living a life of choice, not a life of chance. While we are proud of our Inclusive Education Policy and improvements that have taken place, we know we have a lot more work to do. We will continue to build the capability of schools to make reasonable adjustments, address systemic issues, earn parent confidence and continue to transform our state education system. But the transition – transformation is not as easy, as the Royal Commission has heard over the last four days. It touches every aspect of our education system. Our culture, our policy, our infrastructure, our resourcing, our practice and, most importantly, our parent and student engagement. Every change has to involve all stakeholders, many who have competing views and expectations. But we are committed to continuing to our journey towards a more inclusive education where students of all abilities are welcomed at their local state school, feel safe, are valued, learn alongside their similar-aged peers and achieve their full potential in life.[31]

The benefits of inclusive education

Professor Carrington spoke about the positive influence of inclusion in education, if started at an early age, on the 'life opportunities' of students with disability.[32] She also spoke about the significant influence of inclusion in fostering understanding and respect for diversity in schools at large.[33]

That inclusive education can offer significant benefits to all students and the community as a whole was a theme that emerged strongly during Public hearing 2. So too, did the proposition that students with disability should be given the opportunity to participate in mainstream education, with appropriate supports, whenever that is achievable.

We heard evidence about inclusive education practices used by teachers that enable students of different abilities to learn together in the same classroom, including the practice of co-teaching. Under this model, co-teachers teach in one classroom and work collaboratively to support students who are learning at different levels of the curriculum. This model can enable more time to be spent with learners who need extra support.[34]

Other inclusive education practices we heard about included individual learning plans to enable students to access different levels of the curriculum, the scheduling of breaks and access to quiet spaces for students.[35]

Drivers and forms of violence, abuse, neglect and exploitation

The evidence at Public hearing 2 indicates that there are several key drivers and forms of violence, abuse, neglect and exploitation in the context of the education of children with disability. This evidence was also reflected in submissions received by the Royal Commission and will guide our future work.

These drivers include:

- gatekeeping, and informal and formal exclusion of students
- mistreatment by school staff and other students
- restrictive practices
- lack of adjustments, supports and individualised planning
- low expectations of students with disability and student outcomes, including transitioning into further education
- misuse of disciplinary measures, including suspensions and exclusions
- poor communication
- poor complaint handling
- funding complexities
- insufficient training of the education workforce to increase awareness of disability and insufficient use of communication, educational techniques and suitable materials to support students with disability
- insufficient time and resources available for education staff
- inadequate support for teachers.

The following sections briefly discuss some of these drivers and forms of violence, abuse, neglect and exploitation. The Royal Commission considers it likely that their causes and the measures needed to address them are likely to be interrelated.

Gatekeeping practices

Consistent with submissions received by the Royal Commission,[36] we heard evidence at Public hearing 2 about the existence of 'gatekeeping'.[37] Gatekeeping can take several forms, including schools refusing to enrol a child with disability, offering part-time enrolment only, encouraging enrolment in special/segregated education settings or encouraging home schooling.

We have been told through submissions to the Royal Commission that some schools impose preconditions on families before they accept their child's enrolment, including partial enrolment arrangements or first requiring a formal diagnosis that ensures the child is eligible for disability-related funding.[38]

Mistreatment by school staff and other students

The Royal Commission heard evidence of incidents involving the use of physical force by school staff against students with disability. This included reports by parents of unexplained finger marks and bruising on their children and of rough handling.[39]

Witnesses also spoke about bullying of students with disability by other students and in some cases by teachers.[40] The evidence from academic experts highlighted how negative perceptions or stigmas about students with disability can perpetuate further adverse consequences, such as bullying.[41]

Restrictive practices

We heard evidence on the use of restrictive practices against students. These included physical restraint or confinement alone and without educational materials, either as a method of occupying time or in response to behaviours of concern.[42] Submissions received by the Royal Commission referred to the same practices. Witnesses and some submissions also spoke of instances of chemical restraint, such as schools asking parents to medicate their children as a way of addressing behaviours of concern.[43] Information received in submissions and at the hearing is consistent with a recent comparative study of the regulation of restraint and seclusion in Australian government schools, which found that 'restraint and seclusion are used in school settings for a variety of purposes beyond or in addition to a protective purpose, including as a means of coercion, discipline, convenience or retaliation'.[44]

The Australian Human Rights Commission (AHRC) pointed out that the National Framework for Reducing and Eliminating the Use of Restrictive Practices in the Disability Service Sector (2013) only applies to disability services and that there are no national guidelines directly addressing restrictive practices in educational settings.[45] The AHRC also noted that there are significant variations between states and territories on the use of restrictive practices in schools.[46] Several Australian jurisdictions have recently reviewed their policies and guidelines on restrictive practices in an effort to provide greater clarity on their use in school settings.[47] However, a recent comparative study indicates that the framing of policies and guidelines has occurred in a 'piecemeal fashion with little guidance provided at a national level'.[48]

An advocacy witness informed us about the obstacles faced when legal redress was pursued for the inappropriate uses of restrictive practices. These included favouring staff wellbeing and versions of events where the student with disability was not considered to be a 'reliable witness', with investigations rarely proceeding.[49] She observed that many families supported by her organisation were reluctant to seek further redress through complaints mechanisms and often lacked the financial and emotional resources to do so.[50]

Some advocates and the AHRC have also pointed out in submissions to the Royal Commission that there is a lack of data on the use of restrictive practices in schools, making it harder to know the extent to which they are used against students with disability.[51]

Lack of adjustments, supports and individualised planning

Evidence at Public hearing 2 revealed that students with disability do not always receive the adjustments or supports they need to have proper access to education and participation in school life.[52] Further, there is sometimes a lack of individualised planning for the student's needs and, if there is a plan, it may not be properly implemented or implemented at all.[53]

In this context, the witnesses spoke of adjustments including access to physical items (such as equipment and materials) and differentiated teaching methods, including allowing for breaks.[54] An adjustment can range from simple changes, such as timetabling to ensure a student with mobility difficulties is not in an upstairs classroom, to more complex adjustments developed with help from allied health professionals, such as occupational therapists and speech pathologists. Evidence at the hearing provided examples of a lack of access to necessary equipment or items and inflexibility in the use of techniques to assist learning.[55]

We also received information from submissions that schools sometimes deny students with disability access to the adjustments they need to receive a quality education,[56] and that this occurs in primary, secondary and further education stages.[57]

The inclusive education teachers from the Queensland Department of Education each gave evidence that under-resourcing of teaching staff remains a significant barrier for a school to understand the needs of students with disability and to provide appropriate accommodations to meet students' needs.[58]

A lack of adjustments, supports and individualised planning, or poor implementation of the same, will often mean that the student with disability is not receiving a safe, inclusive and quality education and is therefore experiencing educational neglect.

Low expectations and exclusion as a potential form of neglect

A consistent theme that emerged during Public hearing 2 was that school staff often had low expectations of students with disability.[59] Parents recounted how their children were not treated as 'authentic learners' and were excluded from activities undertaken by their peers due to an expectation that they would not be able to participate.[60] Advocacy witnesses spoke of parents who fought against their children being withdrawn from standard curriculum classes and sent to participate in 'life-skill' classes instead.[61] We heard that students labelled as having 'complex disabilities' are particularly vulnerable to assumptions that can result in exclusion from activities and that these assumptions can lead to abuse and neglect. The Royal Commission is concerned that this can also adversely affect transitioning into further education.

The evidence received at the hearing on low expectations is consistent with submissions from individuals and advocacy organisations received by the Royal Commission. For example, Children and Young People with Disability Australia submitted that some families believe that teachers and support staff do not have high expectations of their children with disability.[62] Family Advocacy in New South Wales had similar 'overwhelming reports' of low expectations.[63] Other submissions told us that educators sometimes assume that the potential of a student with a disability to learn, thrive and make decisions is limited.[64]

Misuse of disciplinary measures, including suspensions and exclusions

We heard evidence about the use of disciplinary measures, including suspensions, against students with disability, which can occur where school staff struggle to understand the nature and manifestations of the student's disability.[65]

Witnesses told us of the perception of parents that behaviour plans implemented by schools as a disciplinary measure can lack mechanisms or goals for positive reinforcement, with the general attitude of schools being to 'deal' with behavioural issues rather than to work through them.[66] We heard evidence about 'informal' suspensions to manage behaviour. Actions ranged from using a reflection or detention room to requesting or encouraging parents to collect students from school or not bring them to school rather than have the school place them under formal suspension.[67]

Parents also expressed concerns about suspensions being used as a form of 'demoralisation' to discourage continued enrolment.[68] Parents experienced distress, harassment and anxiety about the frequency of telephone calls received from schools about their child.

Data currently available to the Royal Commission from Queensland indicates that students with disability are suspended at a higher rate than students without disability.[69]

Poor communication and collaboration leading to potential neglect

The development of positive relationships between students with disability and their parents and school staff is likely to be a key factor for a safe, inclusive and quality education.[70] During the hearing, we were told of the difficulties that families and children with disability can face in communicating with educators and developing collaborative and positive relationships.

We also heard evidence of how relationships with teachers can easily become 'fraught' when there is a misunderstanding or disagreement, with parents and teachers alike often perceiving 'reactivity' and defensiveness from the other party.[71] For example, disputes can arise over whether an adjustment is reasonable or, even when agreed in a support plan, is being provided.

This evidence about the impact that positive and negative relationships between students, their families and school staff can have is also consistent with a number of submissions that the Royal Commission has received. Submissions have stated that collaboration between school staff, family, students and professional experts is important to ensure a holistic understanding of the needs of students with disability.[72]

Poor complaint handling within the education system in response to allegations of violence, abuse, neglect and exploitation

At the hearing we heard that parents of students with disability who would like to raise concerns about the student's educational experience can be reluctant to complain, fearing negative consequences for the student, including putting their enrolment at risk.[73] A lack of financial or emotional resources or institutional awareness are other factors that can prevent families from making or pursuing complaints.[74]

We also heard evidence that when a parent does complain, they are sometimes directed in the first instance to attempt to resolve the complaint with the classroom teacher, who is often the subject of the complaint.[75] Unsurprisingly, that process can be damaging to the ongoing relationship between the parent and the teacher.

Good complaints procedures and handling, with in-built protections for those making complaints, are an essential part of ensuring that schools and governments are accountable for their actions, and respond efficiently and appropriately to complaints. This is particularly important when the complaint involves violence against, and/or abuse, neglect or exploitation of, a student with disability.

Funding complexities

The education of students in Australia is the subject of joint funding arrangements between the Australian and state governments.[76]

Australian Government funding of disability in schools is informed by data collected by the Nationally Consistent Collection of Data on School Students with Disability (NCCD) initiative. The NCCD collects data from all Australian schools about students with disability who receive reasonable adjustments at school. Under the NCCD program, schools report on the number of students receiving reportable categories of reasonable adjustments because of a disability defined by the *Disability Discrimination Act 1992* (Cth) (*DDA*).

States such as Queensland have separate programs and funding allocations for students with disability. In Queensland, the key funding model is the Education Adjustment Program (EAP), which allocates state funding to schools to support students with disability. The EAP assists students who are 'verified' according to six categories: autism spectrum disorder, hearing impairment, intellectual disability, physical impairment, speech-language impairment and vision impairment.[77]

Public schools in Queensland are required to collect data about students with disability under both the NCCD initiative and the EAP.

The evidence at Public hearing 2 revealed that there are challenges in working with these two regimes. The eligibility criteria are inconsistent, meaning that some students will fulfil the criteria of one funding arrangement but not another.[78] So, for example, a student may be regarded as having a disability under the NCCD, but not under the state EAP and thus not eligible for specific allocation under the EAP. Witnesses also spoke of the processes being time consuming and involving duplication. Some students who the witnesses considered should be eligible for additional resources were not able to fulfil the criteria.[79]

While some students may not be verified under the EAP for various reasons, most commonly this occurs because the disability does not align with the six categories of the EAP. In one witness's view, this applies a 'medical model' approach to disability.[80] (See Chapter 16, 'Our theoretical approaches' for more information on the medical model of disability.)

We heard of the barriers to EAP verification, which range from socio-economic barriers to geographical challenges for schools in regional and isolated areas that do not have easy access to the specialist services needed for the process.[81]

This process can pose barriers for some First Nations families, who may find it difficult to navigate or who may reject labels and choose not to identify their child as a person with disability.[82]

The data collection obligations under the NCCD are said to be time consuming and onerous. We heard this causes anxiety to teachers, given their perception that there was no direct link to the delivery of required resources and their concern that they will not meet their obligations under the *DDA*.[83]

Insufficient teacher training and education

Evidence at the hearing and information from submissions indicate that workforce capability varies across education settings. Concerns have been expressed that some teachers are not sufficiently able to differentiate the curriculum, provide adjustments and supports or address behaviours of concern.[84] We have also been told that universities are failing to provide substantive training regarding changing approaches in the classroom for students with disability.[85] Research suggests that if teacher education degrees contained a subject on inclusive education, teachers would be more willing to support an inclusive approach in schools.[86] Further, we heard that disability is not considered in great detail during most university teaching qualifications, unless students choose to study electives on the education of students with disability.[87]

Areas for further inquiry

We will continue to consider how education systems across Australia contribute to, or could reduce, violence against, and abuse, neglect and exploitation of, students with disability in public and private education sectors as well as in special/segregated education and mainstream settings. This section sets out the further inquiries the Royal Commission will make arising from the evidence at Public hearing 2 and from information in submissions and responses to issues papers. This includes further exploration of the concept of inclusive education and the role it plays in preventing violence against, and abuse, neglect and exploitation of, students with disability.

Gatekeeping practices as a potential driver of neglect

We intend to further explore the issue of gatekeeping. This will include:

- inquiring into the denial or informal discouragement of students with disability from attending the schools or education settings of their or their families' choice
- factors that contribute to gatekeeping
- the connection between gatekeeping practices and neglect of students with disability.

Mistreatment by school staff and other students, including by bullying and harassment

The Royal Commission will investigate the causes of mistreatment of students with disability by school staff and other students, including bullying and harassment. We will also investigate factors that protect against such mistreatment and measures that can prevent it.

Restrictive practices

The Royal Commission will investigate the use of restrictive practices and how the improper or inappropriate use of such practices can be prevented or even eliminated altogether. This will include:

- consideration of clear policy and practice guidance and training resources for educators to better understand what constitutes restrictive practices and to promote positive behaviour support and management
- better record keeping and expanded and improved data collection, including in the use of restrictive practices and suspension and expulsion rates
- effective and efficient complaints processes.

Lack of adjustments, supports and individualised planning

The Royal Commission will further explore the lack of adjustments, supports and individualised planning experienced by students with disability.

This will include:

- the factors leading to the need for adjustments not being identified
- why adjustments identified as necessary are not being implemented
- the resourcing needed to provide proper adjustments, supports and individualised planning.

Low expectations and exclusion as a potential form of neglect

The Royal Commission will further explore causes of low expectations of students with disability, why some educators and educational environments may have or create low expectations, and the measures that can be taken to counteract such a culture in Australia. We will consider:

- the causes, extent and impact of low expectations of students with disability in education settings and how this can be reduced and eliminated
- the links between culture, inclusion and leadership in education settings and violence against, and abuse, neglect and exploitation of, students with disability in these settings.

Misuse of disciplinary measures, including suspensions and exclusions

The Royal Commission will further explore the misuse of disciplinary measures, including suspensions or exclusions, in response to behaviours of concern. We will consider:

- data on suspensions and expulsion of students with disability from schools, particularly where there is a disproportionate use of suspensions and exclusions for students with disability
- whether schools use suspensions and exclusions (formal and informal) rather than appropriately supporting students with disability and, if they do, the factors that cause or contribute to the use of suspension and/or exclusion rather than other, appropriate measures for dealing with behaviours of concern.

Poor communication and collaboration leading to potential neglect

The Royal Commission will continue to explore the issue of relationships, communication and collaboration between school staff, parents and students with disability, and violence against, and abuse, neglect and exploitation of, students with disability in education settings. This will include exploring the factors that can enhance or detract from the development of positive relationships.

Poor complaint handling in response to allegations of violence, abuse and neglect

The Royal Commission will further inquire into the oversight and complaints mechanisms that exist to respond to allegations of violence against, and abuse, neglect and exploitation of, students with disability in education settings.

Funding complexities

The Royal Commission intends to continue its inquiry into how funding models for schools to support students with disability operate in states and territories and interact with the national NCCD program. We will examine whether some students with disability are falling through the gaps of eligibility and funding requirements imposed by the Australian, state and territory governments.

The Royal Commission will also consider whether the funding arrangements and access to funding and resources could be more streamlined and efficient to reduce educators' time on these administrative tasks.

Funding models

We will also consider best-practice funding models for schools to support students with disability and reduce the incidence of violence, abuse, neglect and exploitation. This will include considering co-teaching models and models that use para-professionals in supporting the learning of students with disability. We will also consider how best to reduce neglect through the use of child-centred education.

Teacher training and education

The Royal Commission intends to examine teacher education and training (pre- and post-qualification) and the extent to which they adequately prepare teachers to educate and support students with disability.

Data collection

Enquiries by the Royal Commission reveal a lack of consistent national data collection for students with disability. Comprehensive and quality data is necessary to meaningfully inform policy. We intend to examine existing data collection models for gaps and recommend ways to address these gaps.

First Nations students with disability

Public hearing 2 did not examine issues that are of particular relevance to First Nations students with disability.

These issues will be the subject of a future hearing, which will consider, among other things:

- the difficulties that EAP verification requirements can present for students with disability, including students with socio-economic disadvantages and First Nations students[88]

- the importance of the celebration and inclusion of culture and disability to support the diverse range of students to feel belonging, acceptance and the ability to achieve[89]
- the importance of schools collaborating with First Nations community leaders and organisations.[90]

Culturally and linguistically diverse students with disability

Public hearing 2 did not examine issues of particular relevance to culturally and linguistically diverse students with disability. These issues will be the subject of a future hearing.

Inclusive education

The Royal Commission will continue to examine the issue of inclusive education, including measures that will encourage more effective programs of inclusive education in mainstream schools.

Conclusion

The Royal Commission will continue to consider how education systems can contribute to, or reduce, violence against, and abuse, neglect and exploitation of, students with disability, including in public and private education sectors, as well as in special/segregated education and mainstream settings.

Endnotes

1 Transcript, Deborah Wilson and Lisa Bridle, Public hearing 2, 4 November 2019, P-38–68.

2 *Universal Declaration of Human Rights*, GA /217(II) (10 December 1948), art 26; *International Covenant on Economic, Social and Cultural Rights*, opened for signature 16 December 1966, 993 UTS 3 (entered into force 3 January 1976), arts 13–14; *Convention on the Rights of the Child*, opened for signature 20 November 1989, 1577 UTS 3 (entered into force 2 September 1990), art 28; *Convention on the Elimination of All Forms of Discrimination against Women*, opened for signature 18 December 1979, 1249 UTS 13 (entered into force 3 September 1981), art 10; *International Convention on the Elimination of All Forms of Racial Discrimination*, opened for signature 21 December 1965, 660 UTS 195 (entered into force 4 January 1969), art 5 (v); *Declaration of the Rights of Indigenous People*, opened for signature 2 October 2007, A/RES/61/295 (entered into force 13 September 2007), art 14.

3 See, for example, United Nations Educational, Scientific and Cultural Organization (UNESCO) and Right to Education Initiative, *Right to education handbook*, 2019, p 32.

4 *Convention on the Rights of the Child*, opened for signature 20 November 1989, 1577 UTS 3 (entered into force 2 September 1990), art 29.

5 Committee on the Rights of the Child, *General comment No. 1 (2001), Article 29 (1), The aims of education*, 26th sess, UN Doc CRC/GC/2001/1 (17 April 2001) [1–2].

6 *Convention on the Rights of Persons with Disabilities*, opened for signature 30 March 2007, 999 UTS 3 (entered into force 3 May 2008), art 24.

7 *Convention on the Rights of Persons with Disabilities*, opened for signature 30 March 2007, 999 UTS 3 (entered into force 3 May 2008), arts 24(2)(a) and 24(2)(b).

8 *Convention on the Rights of Persons with Disabilities*, opened for signature 30 March 2007, 999 UTS 3 (entered into force 3 May 2008), art 24(2)(c).

9 *Convention on the Rights of Persons with Disabilities*, opened for signature 30 March 2007, 999 UTS 3 (entered into force 3 May 2008), arts 24(2)(d) and 24(2)(e).

10 The Committee on the Rights of Persons With Disabilities, *General comment No 4 (2016) on the right to inclusive education*, 16th sess, UN Doc CRPD/C/GC/4, (25 November 2016).

11 Committee on the Rights of Persons with Disabilities, *General comment No 4 (2016) on the right to inclusive education*, UN Doc CRPD/C/GC/4 (2 September 2016) [11].

12 Committee on the Rights of Persons with Disabilities, *General comment No 4 (2016) on the right to inclusive education*, UN Doc CRPD/C/GC/4 (2 September 2016) [39].

13 For example, All Means All, Submission in response to *Education and learning issues paper*, 17 March 2020, p 10; Women with Disabilities Australia, Submission in response to *Education and learning issues paper*, 6 April 2020, ISS.001.00085; Children and Young People with Disability Australia, Submission, 28 October 2019, SUB.100.00115, p 6.

14 Commonwealth Government, Background Paper on the United Nations Convention on the Rights of Persons with Disabilities: Part 2 - The Right to education in article 24, 17 June 2020.

15 The Committee on the Rights of Persons With Disabilities, *Concluding observations on the second and third combined reports of Australia*, UN Doc CRPD/C/AUS/CO/2-3, 22nd sess, (15 October 2019), [45], [46]; Committee on the Rights of Persons With Disabilites, *Concluding observations on the initial report of Australia*, 10th sess, UN Doc CRPD/C/AUS/CO/1 (21 October 2013) [45], [46].

16 Transcript, AAA, Public hearing 2, 4 November 2019, P-21–36.

17 Transcript, AAA, Public hearing 2, 4 November 2019, P-24, P-26 [1–10], P-27 [20–40], P-29 [7–38].

18 Transcript, AAA, Public hearing 2, 4 November 2019, P-30–32, P-34 [11–41], P-35 [10–27].

19 Transcript, AAC, Public hearing 2, 5 November 2019, P-81–87.

20 Exhibit 21.15, QLD.9999.0007.0240.

21 Exhibit 21.14, QLD.9999.0007.0220.

22 Exhibit 21.14, QLD.9999.0007.0220 at 0220.

23 Transcript, Suzanne Carrington, Public hearing 2, 5 November 2019, P-118 [13–17].

24 Transcript, Suzanne Carrington, Public hearing 2, 5 November 2019, P-127 [2–3].

25 Transcript, Suzanne Carrington, Public hearing 2, 5 November 2019, P-118 [31–34].

26 Exhibit 21.14, QLD.9999.0007.0220 at 0220.

27 This is adapted from The Committee on the Rights of Persons With Disabilities, *General comment No 4 (2016) on the right to inclusive education*, 16th sess, UN Doc CRPD/C/GC/4, (25 November 2016) [12]; see Transcript, Deborah Dunstone, Public hearing 2, 7 November 2019, P-284 [5]. General comment No 4 sets out, at pages 4–6, the Committee's view as to the 'core features of inclusive education', namely, whole systems approach, whole educational environment, whole person approach, supported teachers, respect for and value of diversity, learning-friendly environment, effective transitions, recognition of partnerships and monitoring. Inclusive Education Policy, Queensland Department of Education, pp 2–3.

28 Exhibit 21.14, QLD.9999.0007.0220 at 0220.

29 Exhibit 21.14, QLD.9999.0007.0220 at 0220.

30 Transcript, Glenys Mann, Public hearing 2, 5 November 2019, P-135–149.

31 Transcript, Deborah Dunstone, Public hearing 2, 7 November 2019, P-324 [13–26].

32 Transcript, Suzanne Carrington, Public hearing 2, 5 November 2019, P-134 [17–18].

33 Transcript, Suzanne Carrington, Public hearing 2, 5 November 2019, P-134 [13–20].

34 Transcript, Suzanne Carrington, Public hearing 2, 5 November 2019, P-128; Transcript, Catherine Morris, Public hearing 2, 6 November 2019, P-204–205.

35 Transcript, Suzanne Carrington, Public hearing 2, 5 November 2019, P-126; Transcript, Loren Swancutt, Public hearing 2, 6 November 2019, P-194.

36 For example, Victorian Commission for Children and Young People, Submission in response to *Education and learning issues paper*, 18 March 2020, ISS.001.00066, pp 22–23; Autism Aspergers Advocacy Australia (A4), Submission in response to *Education and learning issues paper*, 3 February 2020, ISS.001.00054, pp 30–31; Family Advocacy, Submission, 9 December 2019, SUB.100.00387, pp 7–9; Kathy Cologon, *Towards inclusive education: A necessary process of transformation* (Report, 2019), in Children and Young People with Disability, Submission, 28 October 2019, SUB.100.00115, p 54; Australian Centre for Disability Law, Submission in response to *Education and learning issues paper*, 19 January 2020, ISS.001.00019, p 4.

37 Transcript, Dr Glenys Mann, Public hearing 2, 5 November 2019, P-140–141.

38 For example, Australian Centre for Disability Law, Submission in response to *Education and learning issues paper*, 19 December 2019, ISS.001.00019, p 7; Name withheld, Submission, 9 August 2019, p 4; Name withheld, Submission, 13 July 2020, p 2; Name withheld, Submission, 18 September 2019, p 2.

39 Transcript, Lisa Bridle, Public hearing 2, 4 November 2019, P-54, [6–14].

40 Transcript, AAA, Public hearing 2, 4 November 2019, P-27 [20–40], P-28 [11–37], P-29[11–61]; Transcript, AAC, Public hearing 2, 5 November 2019, P-78 [29–33], P-84–86, P-88–89.

41 Transcript, Suzanne Carrington, Public hearing 2, 5 November 2017, P-129–130.

42 For example, Transcript, AAA, Public hearing 2, 4 November 2019, P-28–29; Transcript, AAC, Public hearing 2, 5 November 2019, P-88.

43 Transcript, Lisa Bridle, Public hearing 2, 4 November 2019, P-55 [10]; Veronica Reynolds, Submission, 14 January 2020, pp 1–2.

44 Tony McCarthy, 'Regulating restraint and seclusion in Australian Government Schools, A Comparative Human Rights Analysis', (2018), vol 18 (2), *QUT Law Review*, p 200.

45 *Australian Human Rights Commission*, Submission in response to *Education and learning issues paper*, 20 December 2019, ISS.001.00022, p 27.
46 *Australian Human Rights Commission*, Submission in response to *Education and learning issues paper*, 20 December 2019, ISS.001.00022, p 27.
47 For example, Deloitte, *Review of Education for Students with Disability in Queensland State Schools*, Report, 2017; New South Wales Ombudsman, *Inquiry into Behaviour Management in Schools: A Special Report to Parliament Under s 31 of the Ombudsman Act 1974*, Report, 2017.
48 Tony McCarthy, 'Regulating restraint and seclusion in Australian Government Schools, A Comparative Human Rights Analysis', (2018), vol 18 (2), *QUT Law Review*, p 195.
49 Transcript, Lisa Bridle, Public hearing 2, 4 November 2019, P-55 [10–26].
50 Transcript, Lisa Bridle, Public hearing 2, 4 November 2019, P-12 [12–13].
51 For example, Children and Young People with Disability Australia, Submission, 28 October 2019, SUB.100.00115, p 15; *Australian Human Rights Commission*, Submission in response to *Education and learning issues paper*, 20 December 2019, ISS.001.00022, p 25–26.
52 Transcript, AAA, Public hearing 2, 4 November 2019, P-24 [30] – 25 [15]; Transcript, AAC, Public hearing 2, 5 November 2019, P-78 [18–27]; Transcript, AAC, Public hearing 2, 5 November 2019, P-87 [26–29], Transcript, Lisa Bridle, Public hearing 2, 4 November 2019, P-59 [10–14].
53 Transcript, AAC, Public hearing 2, 5 November 2019, P-93 [25] – 94 [2].
54 Transcript, AAC, Public hearing 2, 5 November 2019, P-83 [40], P-87 [24].
55 Transcript, AAA, Public hearing 2, P-29, [1–9], Lisa Bridle, Public hearing 2, P-58, [15–18].
56 For example Australian Centre for Disability Law, Submission in response to *Education and learning issues paper*, 19 January 2020, ISS.001.00019, pp 9, 10, 12.
57 For example Lisa McBride, Submission, 23 October 2019, p 6; Nalini Haynes, Submission, 23 October 2019, p 1.
58 Transcript, AAC, Public hearing 2, 5 November 2019, P-95 [12]; Transcript, Loren Swancutt, Catherine Morris and Jewelann Kaupilla, Public hearing 2, 6 November 2019, P-211 [5] – 213 [45].
59 Transcript, Glenys Mann, Public hearing 2, 5 November 2019, P-141 [23–36].
60 Transcript, AAA, Public hearing 2, 4 November 2019, P-24 [15–25].
61 Transcript, Lisa Bridle, Public hearing 2, 4 November 2019, P-52 [24–45].
62 Children and Young People with Disability Australia, Submission, 28 October 2019, SUB.100.00115, p 11.
63 Family Advocacy, Submission, SUB.100.00387, 9 December 2019, p 6.
64 For example, True Relationships & Reproductive Health, Submission, 28 November 2019, SUB.100.00311, p 4; Family Advocacy, Submission, 9 December 2019, SUB.100.00387, p 10.
65 Transcript, Deborah Wilson, Public hearing 2, 4 November 2019, P-47 [32–34], AAC, Public hearing 2, 5 November 2019, P-94 [13–15].
66 Transcript, Lisa Bridle, Public hearing 2, 4 November 2019, P-58 [15–20], P-59 [7–10].
67 Transcript, Deborah Wilson, Public hearing 2, 4 November 2019, P-57, [24–30]; Lisa Bridle, Public hearing 2, 4 November 2019, P-58 [42–44].
68 Transcript, Lisa Bridle, Public hearing 2, 4 November 2019, P-58 [15].
69 The Royal Commission's preliminary analysis of material obtained by the Royal Commission from the Queensland Department of Education in response to a compulsory notice indicates that in 2019, 15% of students with disability enrolled in a Queensland state school received one or more suspensions in the year, compared to 6% of students without disability. Taking repeat suspensions into account, students with disability made up 46% of all suspension incidents in Queensland state schools in 2019.

70 For example, Teresa Iacono, Submission in response to *Education and learning issues paper*, 15 January 2020, ISS.001.00047, p 2; Noah's Ark, Submission in response to *Education and learning issues paper*, 6 February 2020, ISS.001.00050, p 7; Name withheld, Submission in response to *Education and learning issues paper*, 9 February 2020, pp 6–8, 10–11.

71 Exhibit 2-11, 'Statement of Lisa Bridle', 31 October 2019, at 0006; Exhibit 2-12, 'Statement of Witness AAC', 2 November 2019, at 0015.

72 For example Family Advocacy, Submission in response to *Education and learning issues paper*, 2 January 2020, SUB.100.00387, p 6, 8, 19; Noah's Ark, Submission in response to the *Education and learning issues paper*, 6 February 2020, ISS.001.00050, p 6; Kathy Cologon, *Towards Inclusive Education: A Necessary Process of Transformation* (Report, 2019), in Children and Young People with Disability, Submission, 28 October 2019, SUB.100.00115, pp 43, 52; Children and Young People with Disability Australia, Submission, 28 October 2019, SUB.100.00115, pp 6, 43.

73 Transcript, Lisa Bridle, Public hearing 2, 4 November 2019, P-53 [45–48].

74 Transcript, Lisa Bridle, Public hearing 2, 4 November 2019, P-53 [42–44].

75 Exhibit 2-12, 'Statement of Witness AAC', 2 November 2019, at 0018.

76 Public Hearing Report 2 discusses the role the Commonwealth has with respect to the education of students with disability, that is, it observes that the Commonwealth has promulgated the *Disability Standards for Education 2005* under the powers set out in the *Disability Discrimination Act 1992* (Cth). It is also noted that the Commonwealth has the power to make specific provisions for students with disability as an exercise of external affairs power by virtue of implementing provisions of the CRPD. See *Disability Discrimination Act 1992* (Cth) s (12)(8).

77 Transcript, Deborah Dunstone, Public hearing 2, 7 November 2019, P-272 [31–33].

78 Transcript, Jewelann Kauppila, Public hearing 2, 6 November 2019, P-218 [10–13], [22–25].

79 Transcript, Loren Swancutt, Public hearing 2, 6 November 2019, P-217 [26–27], P-222 [5–25].

80 Transcript, Loren Swancutt, Public hearing 2, 6 November 2019, P-221 [21–24].

81 Transcript, Loren Swancutt, Public hearing 2, 6 November 2019, P-217, [30–32].

82 Transcript, Loren Swancutt, Public hearing 2, 6 November 2019, P-220 [13–25].

83 Transcript, Kevin Bates, Public hearing 2, 5 November 2019, P-109 [41–45].

84 Transcript, AAA, Public hearing 2, 4 November 2019, P-34 [10–15].

85 Transcript, Suzanne Carrington, Public hearing 2, 5 November 2019, P-123 [38–43].

86 Transcript, Suzanne Carrington, Public hearing 2, 5 November 2019, P-123 [15–19].

87 Transcript, Suzanne Carrington, Public hearing 2, 5 November 2019, P-99 [3–11].

88 Transcript, Loren Swancutt, Public hearing 2, 6 November 2019, P-220 [13–25].

89 See, for example, the evidence of Judith Fenoglio, Transcript, Fenoglio, Public hearing 2, 6 November 2019, P-237.

90 See, for example, the evidence of Loren Swancutt, Transcript, Swancutt, Public hearing 2, 6 November 2019, P-182; see also the evidence of Jewelann Kauppila, Transcript, Kauppila, Public hearing 2, 6 November 2019, P-183.

Nathan*

*** Name changed and some details removed to protect people's identities. Narrative based on a submission to the Royal Commission. Note that the submission and this narrative did not form any part of the evidence at the public hearing discussed in Chapter 12 of this report.**

In her submission Nathan's mum told us about the day she found her son trying to cut his wrists. 'He was 10,' she said. 'He was being treated so bad that he wanted to hurt himself.'

The problems started in 2017, when Nathan was in grade 6 and attending a mainstream school. Nathan is autistic and has attention deficit hyperactivity disorder and mild intellectual disability. But at that time Nathan had not yet been diagnosed. His mum thought a lot of his struggles were trauma related – but she was open with the school about Nathan's behavioural issues.

Nathan had a bad time at this school. He was bullied by students as well as teachers.

One day Nathan's mum got a phone call from the assistant principal warning her that if Nathan misbehaved one more time they would suspend him. Nathan's mum blamed him for being naughty.

One day Nathan came home crying and hungry. All the other children were given fish and chips as a treat, but Nathan wasn't given any. Nathan's mum emailed the school because she wasn't happy about how they had singled out her son.

But after sending that email Nathan's mum started getting phone calls from the school on an almost daily basis, telling her that Nathan was going to be suspended. They wouldn't give her any information about why.

Nathan was now having severe meltdowns and anxiety, so his mum got a referral for a mental health team, a paediatrician and counselling. At that point, Nathan was fully diagnosed. He then began to receive treatment.

Despite this, Nathan's mum said the school didn't seem to care about his disabilities. They continued to suspend him. He was having anxiety attacks every time he entered the school. He was still getting bullied and picked on.

The school was made aware of this, but it didn't act. Nathan's mum took his situation to the education department. This resulted in the school developing a behavioural plan that, his mum said, 'set Nathan up to fail'.

Then it happened – Nathan felt so bad about things that he tried to cut his wrists. Distraught, Nathan's mum begged the education department to let her take Nathan out of that school and find him another one. But they refused. 'No school would take my son,' she said.

Finally, the education minister was made aware of Nathan's situation and found him a new school.

Nathan is now in year 7 and his mum told us she is happy that he is doing well. But she also remembers what they experienced: 'Our family was torn apart. I resigned from my job. Until this day, the school has never been held accountable for the mistreatment of my child who has a disability. The school system is broken.'

Patrick*

*** Name changed and some details removed to protect people's identities. Narrative based on a submission to the Royal Commission. Note that the submission and this narrative did not form any part of the evidence at the public hearing discussed in Chapter 12 of this report.**

In their submission, Patrick's parents described him as a very capable and intelligent autistic teenager.

They told us that a decade ago they began the process of enrolling Patrick in the local religious school so that he could start at kindergarten the following year.

They chose the school in their local area. Patrick's sister was already going to the school and Patrick's parents explained that, according to the applicable policies, Patrick would be given priority enrolment there.

'We were horrified,' Patrick's mum says, when, having completed all the paperwork, the principal of the school told her that Patrick's enrolment was conditional.

Patrick's parents told us that, in addition to regular school fees, they were expected to pay for an additional staff member for the school from their own pocket. They would also have to pay for the staff member's leave and other entitlements. However, the staff member would be working with all children in the class, not just Patrick.

Patrick's parents declined this option and chose a public school instead, where they say Patrick is thriving.

13. Public hearing 3: The experience of living in a group home for people with disability

Key points

- The main purpose of the Royal Commission's third public hearing was to inquire into the experiences of people with disability living in group homes.
- Of particular concern was whether living in a group home heightens the risk of violence, abuse, neglect or exploitation for people with disability.
- Twenty-eight witnesses gave evidence, including people with disability who had lived in a group home.
- The evidence indicates that some and perhaps many group homes do not provide the quality of life and protection from abuse residents have a right to expect.
- We heard from people with disability about being deprived of choice when seeking accommodation and when living in a group home – including choice about where and with whom to live and their service provider.
- We heard how lack of choice can result in a loss of control and autonomy and exclusion from social, economic and cultural life, and can lead to exposure to violence, abuse, neglect and exploitation.
- Consistent themes were the importance of culture, and the need for better training and monitoring of disability support staff in group homes, in recognition of the important responsibilities they have.
- From Public hearing 3, the Royal Commission has identified factors leading to violence against, and abuse, neglect and exploitation of, people with disability living in group homes and other forms of supported accommodation. This information, along with the proposals for addressing these factors put forward at the hearing, will guide the Royal Commission's future work in this area.

Introduction

The Royal Commission held Public hearing 3: The experience of living in a group home for people with disability, from 2 to 6 December 2019 at the Melbourne Convention and Exhibition Centre.

As outlined in the Glossary, the Royal Commission uses the term 'group homes' to describe houses that accommodate a number of people with disability as their residential home. Disability service providers are usually responsible for coordinating both the physical accommodation and provision of supports to residents in the home.

The main purpose of Public hearing 3 was to inquire into the experiences of people with disability living in group homes. The Royal Commission was particularly concerned to investigate whether living in a group home heightens the risk of violence, abuse, neglect or exploitation for people with disability.

The themes and issues examined at this public hearing have also been raised with the Royal Commission through submissions, responses to issues papers, research and community engagement. Chapter 17, 'Emerging themes and key issues' provides a more detailed discussion of the emerging themes and key issues raised in the inquiry so far.

The Royal Commission decided to focus on group homes in one of its early public hearings because a person's home is where they should feel and be safe and secure. A home is central to a person's life, dignity, independence and wellbeing. The importance of a home is affirmed in Article 19 of the United Nations *Convention on the Rights of Persons with Disabilities (CRPD)*, which requires all States Parties, such as Australia, to:

> recognize the equal right of all persons with disabilities to live in the community, with choices equal to others.[1]

This right encompasses the opportunity for people with disability to choose their place of residence and with whom they live, on an equal basis with others.

Public hearing 3 concentrated on a number of important issues related to violence abuse, neglect and exploitation occurring in group homes. They are:

- the right of people with disability to choose where and with whom they live
- the emergence of the group home model and its impact on the housing options and living conditions of people with disability, particularly in Victoria
- the causes of violence against, and abuse, neglect and exploitation of, residents of group homes in Victoria
- the effectiveness of laws, policies and key government agencies in protecting residents with disability living in group homes from violence, abuse, neglect and exploitation
- alternatives to the group home model for people with disability who want to live independently.

We have published a detailed report on Public hearing 3, which is available on the Royal Commission website. This chapter is based on that hearing report but does not cover every issue discussed there. References in this chapter are to sections and paragraphs of the hearing report rather than to the evidence presented at the hearing. Detailed references to the evidence and more information about the witnesses can be found in the hearing report.

Witnesses

The Royal Commission heard evidence from 28 witnesses at Public hearing 3.[2] They can broadly be divided into six categories:

- direct experience witnesses[3]
- advocates[4]
- representatives from government and oversight bodies[5]
- service providers[6]
- experts and academics[7]
- witnesses proposing alternatives to group homes.[8]

We recognise that some witnesses could be placed in more than one of these categories and others may not fit squarely within any one of them.

The evidence of the direct experience witnesses was particularly significant. They described being deprived of choice when required to live in shared supported accommodation. They explained that a lack of choice leads to loss of control and autonomy and to the exclusion of people with disability from the community's social, economic and cultural life.[9] Lack of choice can also lead to residents of group homes or other supported accommodation being exposed to violence, abuse, neglect and exploitation.[10]

Key themes

Seven key themes emerged from the evidence given at Public hearing 3. Each theme is important because it bears on the measures that are needed to eliminate, so far as possible, violence against, and abuse, neglect and exploitation of, people with disability living in group homes and other forms of supported accommodation.

The seven themes are:

- the consequences of deinstitutionalisation
- autonomy for people with disability
- safety in group homes
- safety strategies
- reporting of violence, abuse, neglect and exploitation
- alternatives to living in a group home
- redress for survivors of violence, abuse, neglect or exploitation.

Consequences of deinstitutionalisation

The institutionalisation of people with intellectual and psychosocial disability began in Europe in the 17th century.[11] People with disability were usually accommodated in large segregated facilities. In Australia, these facilities originated in colonial times and came to be operated mainly by state governments. Chapter 1, 'Why this Royal Commission is needed' provides a brief overview of the history of institutionalising people with disability in Australia.

The Royal Commission heard evidence from a number of witnesses about the living conditions in institutions in Victoria that have now closed. One witness stated that living in a large institution was 'hell'. He considered that 'staff could do what they liked', for example, beating residents as punishment for perceived misbehaviour.[12] Another witness recounted having been sexually abused over three years by a bus driver who worked at the institution where she lived.[13]

Since the 1960s, a process of deinstitutionalisation has occurred in Australia.[14] This has involved moving people out of large institutions and directing them towards smaller and more dispersed community-based housing.[15] This process was linked (or was supposed to be linked) to greater support for people with psychosocial and intellectual disabilities.[16]

The factors that drove deinstitutionalisation in Australia included:[17]

- mounting evidence, including government reports and academic work published in Australia and internationally, of overcrowding, disease, abuse, neglect and restriction of individual freedoms that typified life for residents in large institutions
- the advocacy of the disability rights movement from the 1960s onwards
- the gradual acceptance of the principle of 'normalisation'; that is, the idea that people with disability should have opportunities for life as close as possible to an ordinary life that other members of the community enjoy, an idea given impetus by the *CRPD*
- reforms in the delivery of human services by governments and a general shift away from policies of segregation
- changes in the approach of health professionals towards people with disability, particularly the treatment of psychosocial disability.

Deinstitutionalisation was a well-intentioned process, but it coincided with a dramatic increase in the number of people with disability who became homeless or were incarcerated as the result of coming into contact with the criminal justice system.[18] Accommodation for people with disability was often unavailable or unfit for purpose, particularly for people with cognitive disability or who experienced mental illness.[19] Despite the closure of the large state-run institutions, many people with disability continued to live in an institutional environment or in ‘congregate settings’ such as aged-care nursing homes or ‘clustered’ smaller facilities.[20]

The evidence at Public hearing 3 suggested that the group home model was a ‘direct response’ to deinstitutionalisation.[21] People with disability were moved out of institutions but needed other places to live. Some witnesses suggested that the main rationale for the establishment of group homes for people with disability was to achieve ‘economies of scale’.[22]

Chapter 17 discusses the ongoing impact of deinstitutionalisation in more detail.

Not all group homes are poorly run or expose residents to avoidable risks of violence, abuse, neglect or exploitation. The evidence at Public hearing 3 indicates, however, that some – perhaps many – group homes fail to deliver the quality of life and protection from abuse that residents have a right to expect. One witness characterised underperforming group homes as often reflecting a ‘misalignment between the values of staff who held the power in the group home and the mission of the wider organisation responsible for management of the home’.[23]

Autonomy for people with disability

The key theme emerging from Public hearing 3 was the paramount importance of choice and control for people with disability. This includes choice about where and with whom to live.[24]

Choice about where and with whom to live

Witnesses frequently decried the lack of choice for people with disability seeking accommodation or already residing in group homes. The witnesses stressed that there can be serious consequences if a person lacks control over basic elements in their life – which include exposure to the risk of violence, abuse, neglect and exploitation.

The evidence established that in most Australian jurisdictions there is a chronic lack of accessible and affordable housing for people with disability.[25] Since demand for supported accommodation exceeds supply, people often have to join long waiting lists for a place in a group home or other supported accommodation.[26] As a shortage of accommodation inevitably requires priority to be given to people in extreme need, the allocation of places as vacancies arise is effectively crisis-driven. This means people with disability have little opportunity to select their own accommodation or to determine whether they are likely to be compatible with their co-residents.[27]

It is hardly surprising that conflicts or other difficulties can arise when people are forced to live together, particularly where there is little or no attempt to assess compatibility with coresidents or staff. A lack of choice not only exposes people with disability to the risk of violence or abuse, but can leave a victim of abuse with no option but to continue living in the same accommodation in which the perpetrator works or lives. One witness recounted a case where a resident of a group home was sexually assaulted by another resident.[28] The assault was reported to the police, yet 18 months later both victim and perpetrator remained in the same accommodation.

The consequences of a lack of alternative options also applies when a group home resident is experiencing institutional neglect – they cannot solve the problem by moving to more suitable accommodation if no such accommodation is available.

Choice of service provider

Witnesses with disability, their supporters and experts agreed that it is important for people with disability living in group homes and other supported accommodation to be able to choose their service providers.[29] The relationship between resident and support worker is critical because of the intimate nature of the support services on which the resident often relies. As with a lack of accommodation options, a lack of choice over service providers and their staff, together with other systemic failings such as poor culture and an absence of supervision and reporting, means that a perpetrator of violence, abuse, neglect or exploitation can continue to be engaged in the same group home or accommodation service.

Most people entering group homes have no choice about the provider of support services.[30] Witnesses were particularly critical of the practice of a landlord also acting as or nominating the service provider for residents. This was said to create a 'power dynamic' that often works against the interests of residents.[31]

Service delivery

Witnesses criticised the 'one-size-fits-all' model of service delivery adopted by some group homes.[32] A characteristic of this model is that working practices are staff-centred rather than resident-centred. For example, rosters and activities are organised around the needs of support staff rather than those of the residents. The result is often that residents have little or no choice about the food they can eat, when and where they eat, when they can go to the bathroom and when they have to go to or get out of bed.

If the routine of a group home is given priority over residents' needs, the risk of violence, abuse, neglect and exploitation is likely to increase. As the Victorian Disability Commissioner observed, 'People with disabilities have a right to receive individualised support services that are flexible and adaptable to the person, not the other way round.'[33]

Safety in group homes

Evidence at Public hearing 3 addressed the punitive culture that characterises some group homes.[34] A punitive culture among the staff of a group home can create a climate in which violence against, and abuse, neglect and exploitation of, residents is more likely to occur.[35] It can also make ineffective the safeguards in place to protect residents and to ensure that any misconduct or systems failures are reported and acted on.

The expert evidence at Public hearing 3 identified factors that contribute to a poor culture in group homes. They include staff:[36]

- regarding residents as ‘other’ and using derogatory terms to describe the people for whom they care
- not accepting that their role extends beyond providing physical care to supporting people to live comfortably in their own home and participate in the community
- resisting new ideas and the influence of ‘outsiders’ in the conduct of the group home.

A further factor increasing risks to residents of group homes is said to be the ‘casualisation’ of support work, that is, that the workforce is for the most part engaged on a casual basis, usually for a short term. This appears to have been a feature of the disability support workforce for a considerable time, both before and after the transition to the National Disability Insurance Scheme (NDIS).[37] One witness described the casualisation of staff as a ‘recipe for disaster’.[38] The witness referred to the experiences of her daughter, who has autism and has had to cope with a succession of casual staff who do not know her.

Evidence at Public hearing 3 indicates that there are service providers that engage well-trained and dedicated staff who provide high standards of support and care in group homes.[39] But a consistent theme in the evidence was the need for better training and monitoring of disability support staff in group homes to minimise the risk of violence, abuse, neglect and exploitation.[40]

The evidence also suggested that the safety and wellbeing of residents is enhanced if disability support workers understand and accept that their role includes encouraging people with disability to speak up for themselves.[41] Equally, protections must be in place for staff who report concerns about ill-treatment or neglect of residents.

Safety strategies

For people with disability, like people without disability, being safe means feeling physically and emotionally safe, having their needs met and feeling capable of making their own decisions.

People with disability living in closed environments such as group homes usually have limited opportunities to establish relationships. Their interactions are generally confined to disability service providers, other staff and co-residents. Witnesses stressed the importance of people with disability having access to the community at large and building trusting relationships with a range of people outside the closed environment.[42] Developing normal networks and genuine relationships is seen as an important means of reducing the risk of violence, abuse, neglect and exploitation.[43]

Independent advocacy and self-advocacy emerged as key factors in promoting the safety of people with disability living in group homes.[44] If people with disability are aware of their rights and how to exercise those rights, they are more likely to recognise and report threats to their safety or wellbeing. The safety of residents is further protected when family members or other trusted supporters advocate on their behalf.[45]

Reporting violence, abuse, neglect and exploitation

The reporting of violence against, and abuse, neglect and exploitation of, people with disability is critical to ensuring effective responses, particularly in the closed environment of group homes and other supported accommodation. We heard from some experts that there are limits to the effectiveness of a compliance-based approach in assessing the quality of a disability service and ensuring that services promote the safety of residents in group homes.[46] But that argument perhaps reinforces the importance of establishing rigorous quality assurance systems and external monitoring of disability services and safety protocols.

Alternatives to living in a group home

The group home model appears to have been designed primarily to support people with disability to transition from living in institutions to living independently in the community, rather than to provide a permanent, effective solution to the housing needs of people with disability.[47] If this is correct, it is perhaps not surprising that the model has attracted so much criticism as it has become the long-term approach to providing accommodation for people with disability who have high support needs. The experiences of many people who have lived in group homes suggest that the Royal Commission should explore alternatives to group homes that offer people with disability greater choice, control and autonomy over where and with whom they live.

A number of witnesses who have lived in group homes gave forceful evidence of the benefits of transitioning to accommodation of their own choice, usually with the support of funding through the NDIS.[48] Public hearing 3 did not examine the operation, arrangements or the impact of the NDIS on accommodation services in Victoria. Chapter 17 includes discussion of what the Royal Commission has heard about the NDIS through submissions, community engagement (including community forums), and responses to issues papers. The NDIS will be examined in more detail in the Royal Commission's future work, with the benefit of hearing directly from the National Disability Insurance Agency (NDIA). Appendix D provides a brief overview of the NDIS.

While some people require support in their new homes, the opportunity to select their accommodation enables them to enjoy more freedom and independence. Taking advantage of that opportunity is not without risks. Even people who live independently, supposedly with adequate support, can be vulnerable to abuse or gross neglect. But the evidence at Public hearing 3 spoke eloquently of the advantages of people with disability exercising choice and control in relation to their accommodation.

The NDIS has contributed to the emergence of new models for providing accommodation and services to people with high support needs. The effectiveness of these models will need to be evaluated, but they perhaps mark the beginning of a transition from group homes towards other forms of supported accommodation.

Redress for people with disability who experience violence, abuse, neglect and exploitation

Public hearing 3 was the first opportunity the Royal Commission had to hear from a disability service provider about the extent of assistance, advice and compensation provided to people with disability who have experienced violence, abuse, neglect or exploitation while in a group home or other supported accommodation.[49] The Royal Commission has not made findings about particular cases, but it is clear that the question of redress, including compensation for serious harm, is worthy of further investigation.

This is a topic that the Royal Commission is likely to examine with other service providers and governments in future hearings.

Findings and areas for further inquiry

The evidence presented at Public hearing 3 is sufficiently clear for us to identify factors leading to violence against, and abuse, neglect and exploitation of, people with disability living in group homes and other forms of supported accommodation. The identification of these factors, with the proposals for addressing them put forward at the hearing, will guide the future work of the Royal Commission.

This section sets out the further inquiries the Royal Commission intends to carry out arising out of the evidence given at Public hearing 3.

Autonomy

The Royal Commission intends to explore potential reform of laws, policies and practices that will enable people with disability who reside in group homes or other forms of supported accommodation to exercise and enjoy their right to autonomy. We will consider:

- strategies to increase the stock of suitable accommodation, to create opportunities for people with disability to have and exercise choice over their accommodation settings
- mechanisms for providing people with disability with the support services and individual advocacy necessary for them to express their preferences and, so far as possible, to obtain accommodation that matches their preferences
- facilitating people with disability to have choice in selecting co-residents
- ensuring separation between providers of accommodation, and providers of support services for people with disability residing in group homes
- identifying best practice, for providers of group homes and disability services to follow.

Culture

The Royal Commission intends to examine measures that could improve the culture of providers of accommodation and disability services. The aim is to eliminate, so far as possible, violence against, and abuse, neglect and exploitation of, people with disability residing in group homes or other supported accommodation. We will consider:

- codifying the legal responsibilities of providers of accommodation and disability support services to promote practices and cultures that prioritise the needs and desires of residents and maximise their opportunities for choice and control
- requiring providers of accommodation and disability support services to articulate clear objectives and report on progress towards achieving those objectives
- refining standards to be used in evaluating the success of providers of accommodation and disability support services in achieving their objectives
- applying sound design principles in the construction and configuration of homes suitable for people with disability, to enhance residents' dignity and quality of life.

Qualifications and experience of support staff

The Royal Commission intends to investigate how disability support workers in group homes and other forms of supported accommodation can better meet the needs and wishes of the people with disability they support. We will consider:

- measures needed to ensure that disability support workers receive the training and acquire the experience necessary to engage with people with disability in a way that promotes choice, control and safety for residents and allows workers to earn their trust
- training programs for disability support workers that claim success in promoting choice, control and safety among residents of group homes and other supported accommodation
- incentives or other measures to encourage service providers to reduce reliance on disability support workers employed on a casual basis
- more effective screening of disability support workers and others providing services to people with disability living in group homes and other supported accommodation
- policies and procedures that monitor more closely the quality of services provided to residents of group homes and other forms of supported accommodation, including policies and procedures relating to continuous training programs for staff

- examples of best practice in Australia and elsewhere that, if adopted, would enhance the quality of life enjoyed by residents of group homes and other forms of accommodation for people with disability.

Enhancing safety

The Royal Commission will investigate how the safety of people with disability living in group homes or other supported accommodation can be enhanced. We will consider:

- the measures, including increased funding, needed to ensure that all residents of group homes and other supported accommodation have access to individual advocacy
- programs to develop the capacity of residents of group homes and supported accommodation to act as self-advocates
- the adequacy of existing systems at federal, state and territory levels for supervision and monitoring of staff
- the adequacy of those systems for identifying, reporting, investigating and responding to cases of alleged violence against, and abuse, neglect and exploitation of, people with disability in group homes and supported accommodation. If they are not adequate, we will consider how the systems can be improved
- whether the approach of the NDIS Quality and Safeguards Commission (NDIS Commission) to identifying, reporting, investigating and responding to cases of violence against, and abuse, neglect and exploitation of, people with disability living in group homes or supported accommodation is adequate and, if not, how it can be improved.

Alternatives to group homes

The Royal Commission will examine whether there are alternatives to group homes for people with disability. As part of this investigation, we will consider:

- whether the group homes model can ever provide residents with enough choice and control to give practical effect to their right to autonomy
- alternatives to group homes for people with severe physical or intellectual disability
- the benefits and risks associated with encouraging alternative forms of accommodation
- how people with disability can be supported in the transition to alternative forms of accommodation
- the safeguards necessary to ensure that alternative forms of accommodation do not expose people with disability to violence, abuse, neglect and exploitation.

Redress

The question of redress has received relatively little attention to date in submissions to the Royal Commission, responses to our issues papers, or during community engagements. Nonetheless, the question is important. The Royal Commission proposes to investigate:

- the forms of redress available to people with disability who are subjected to violence, abuse, neglect or exploitation while residing in group homes or supported accommodation
- measures that should be taken to ensure that when violence, abuse, neglect or exploitation occurs, people receive independent advice and support to enable them to pursue the remedies available to them
- whether it is feasible to establish a scheme to compensate people with disability who have sustained serious harm from violence, abuse, neglect or exploitation in circumstances where no other redress is available to them.

Endnotes

1 *Convention on the Rights of Persons with Disabilities*, opened for signature 30 March 2007, 999 UNTS 3 (entered into force 3 May 2008), art 19.
2 Report of Public hearing 3, [37–236].
3 Report of Public hearing 3, [37–84].
4 Report of Public hearing 3, [85–113].
5 Report of Public hearing 3, [176–210].
6 Report of Public hearing 3, [222–237].
7 Report of Public hearing 3, [133–175].
8 Report of Public hearing 3, [116–131].
9 Report of Public hearing 3, [286–301].
10 Report of Public hearing 3, [266].
11 Report of Public hearing 3, [136–139], [268].
12 Report of Public hearing 3, [270].
13 Report of Public hearing 3, [274].
14 Report of Public hearing 3, [137], [267].
15 Report of Public hearing 3, [137].
16 Report of Public hearing 3, [137].
17 Report of Public hearing 3, [275].
18 Report of Public hearing 3, [182].
19 Report of Public hearing 3, [276].
20 Report of Public hearing 3, [276].
21 Report of Public hearing 3, [278].
22 Report of Public hearing 3, [278].
23 Report of Public hearing 3, [280].
24 Report of Public hearing 3, [54], [72], [83], [89].
25 Report of Public hearing 3, [131], [140], [285].
26 Report of Public hearing 3, [285].
27 Report of Public hearing 3, [101], [286].
28 Report of Public hearing 3, [106].
29 Report of Public hearing 3, [109], [180], [259], [290], [328], [330], [372].
30 Report of Public hearing 3, [292].
31 Report of Public hearing 3, [292].
32 Report of Public hearing 3, [198], [286], [296].
33 Report of Public hearing 3, [296].
34 Report of Public hearing 3, [304–305].
35 Report of Public hearing 3, [303–307].
36 Report of Public hearing 3, [307].
37 Report of Public hearing 3, [310].
38 Report of Public hearing 3, [310].
39 Report of Public hearing 3, [63], [171].
40 Report of Public hearing 3, [59], [64], [189], [193], [200], [202], [207].
41 Report of Public hearing 3, [87], [113], [306].
42 Report of Public hearing 3, [84], [89], [101], [107], [109], [121], [157], [167], [254], [315], [332].
43 Report of Public hearing 3, [127], [175], [313], [315], [316].
44 Report of Public hearing 3, [113], [317–318].
45 Report of Public hearing 3, [317–318].
46 Report of Public hearing 3, [324].
47 Report of Public hearing 3, [228], [333].
48 Report of Public hearing 3, [325–330].
49 Report of Public hearing 3, [338–343].

Naomi*

*** Name changed and some details removed to protect people's identities. Narrative based on a submission to the Royal Commission. Note that the submission and this narrative did not form any part of the evidence at the public hearing discussed in Chapter 13 of this report.**

Naomi has a range of disabilities, including cerebral palsy and intellectual disability. In her submission she told us she has lived in a variety of supported accommodation settings, where she was bullied and psychologically abused.

One of the places she lived in was a hostel that accommodated about 50 people. Naomi told us she was bullied and socially isolated – staff would tell everyone to stay away from her. Naomi would be 'told off' and sent to her room for things that she couldn't help – things that were part of her disability. Staff would repeatedly threaten Naomi, saying, 'we will call your family', when they knew Naomi didn't want her family involved because of 'what [she] grew up with'.

Naomi told us that the residents were warned if they reported anything going on at the hostel they would be evicted, so no-one did. Eventually she did speak up – and, just as she had been warned, she was evicted.

Naomi became homeless, couch surfing and staying in hostels. It took six months to find appropriate accommodation. As a result of being homeless, she ended up in abusive situations that affected her physical and mental health.

Naomi is moving to supported disability accommodation, and she's optimistic about the new living arrangements she is moving to. She hopes this set-up will give her 'more choice and control' and she'll be treated with 'dignity and respect'.

Naomi reflects on her experiences: 'Nobody should have gone through what I went through.' She has a lot of ideas about how things can get better. She believes organisations and individuals should be held to account when they have done something wrong. There should be faster timelines for NDIS funding – especially when a person is about to become homeless. Also, staff should receive better training on different types of disability.

Naomi also told us she thinks people with disability should have more affordable accommodation choices. 'People with severe disabilities,' said Naomi, 'should still have a choice of where they would like to live.'

Gerry and Pete*

*** Names changed and some details removed to protect people's identities. Narrative based on a submission to the Royal Commission. Note that the submission and this narrative did not form any part of the evidence at the public hearing discussed in Chapter 13 of this report.**

Gerry has global aphasia. He is non-verbal and his ability to understand spoken language is limited. He cannot leave his bed and lives in a care home. Gerry's brother Pete, his legal guardian, made a submission to the Royal Commission.

Pete said he noticed a change in Gerry's behavior a few years ago. Gerry had mood swings and would lash out and become combative when people touched him during their care for him. Pete told us he witnessed staff using force until Gerry submitted. 'People put it down to his mental capacity from his stroke,' Pete said. Gerry also stopped eating and drinking, which led staff to tell Pete that Gerry 'was looking to end his life'.

Pete said this went on for around two months until they discovered Gerry had a fractured hip and was in severe pain. The hip had been fractured for several months and the fracture was so bad Gerry needed a hip replacement.

Wanting to understand how and when the fracture happened, Pete asked to see an incident report, but no incident had ever been reported.

'How a bed bound, non-verbal person can have such a severely fractured hip and [there is] no incident report of any trauma' confounded Pete.

Pete complained to the group home provider and the ombudsman. The provider conducted a limited internal investigation but found no evidence about where or how the injury happened. Pete said he was told it was a 'pathological injury (caused by disease)' but when he requested tests to confirm or deny this, the results clearly stated Gerry 'was at no risk of fractures'.

Eventually, Pete said, he was told to 'move on as there is never going to be a conclusion to how he got the injury'.

Gerry has been 'left in a condition with severe pain that has had a major effect on his life even till this day'. Pete told us he is concerned Gerry's injury was caused by either abuse or neglect. He considers people with global aphasia are at extreme risk of violence and abuse because they can't report the abuse.

Pete said the system has failed Gerry. He would like to see more comprehensive training for staff working with people with global aphasia because they need to be supported very differently to people who are verbal. He told us he would also like CCTV to be mandatory in care homes and believes if staff are doing the right thing they shouldn't mind cameras being in place.

Pete said Gerry's experience has left him feeling disillusioned. 'From all the investigations I've done, the complaints I've made, the service providers have more rights than the disabled people who live in these homes.' He worries about people in Gerry's situation who don't have a strong advocate. 'What if my brother didn't have a determined person like me where would he be now?'

Brendan and Sandra*

*** Names changed and some details removed to protect people's identities. Narrative based on a submission to the Royal Commission. Note that the submission and this narrative did not form any part of the evidence at the public hearing discussed in Chapter 13 of this report.**

Brendan is in his thirties and lives in a group home in New South Wales. He has epilepsy, limited vision and a cognitive disability. Sandra, Brendan's mum, made a submission about how Brendan and the other men he lived with were physically, psychologically and financially abused by the house manager, Belinda.

She said Belinda used to kick Brendan and lock him outside when she came on duty, and would eat in front of him and all the other men while they had nothing. The men never went anywhere apart from their day programs.

Sandra told us that sometimes when the house did their weekly shopping Belinda would steal all the groceries and take them home with her. At one point, staff were bringing in food from their own homes for the men or buying food for them. There were no fresh fruit or vegetables in the house, and Brendan was spending all his pension on takeaway food. He lost more than 20 kg.

When Sandra asked about getting the GP in to look into Brendan's weight loss, she says, Belinda insisted it was Brendan's medication that was making him lose weight and claimed she couldn't get a booking with the doctor for several weeks.

Sandra told us Belinda had been abusing Brendan and the other residents for 12 months before the residents' families learned the full extent of it.

She recalls that the service provider called the guardians of all four men to a meeting where they explained what Belinda had been doing, which included stealing thousands of dollars from the men's bank accounts. A member of staff had blown the whistle, and the service provider reported the abuse and theft to the police.

Sandra said she and the other families were told that because the men are all non-verbal they could not get up in court and swear to what had happened. So, despite the full report from the whistleblower, if the case went to court Belinda would be acquitted and then probably sue the service provider for unfair dismissal.

The provider reimbursed the stolen money to the residents, dismissed all the staff and brought in new staff, Sandra told us.

She says that the service Brendan and his housemates now receive is 'wonderful' and the staff are very caring:

> The group home feels like a HOME. It's decorated nicely, Brendan has 1 to 1 with a carer 3 times a week, where he gets to go to the pool in warmer months, for drives, to the movies, to the shops to buy a car.

The provider has also established a family day at the house every six months, to discuss anything the families are unhappy with.

But Sandra said none of the families are happy that Belinda 'got off scot free'. And Brendan is still traumatised from the times Belinda locked him outside. He will only go outside in the backyard at his group home for a short time, Sandra told us, and never by himself.

Tom*

*** Name changed and some details removed to protect people's identities. Narrative based on a submission to the Royal Commission. Note that the submission and this narrative did not form any part of the evidence at the public hearing discussed in Chapter 13 of this report.**

Tom has an acquired brain injury and limited movement on his left side. He has been living in supported accommodation for the past 10 years or so with several other people, and during that time has seen his fellow tenants abused, exploited and neglected on a daily basis. 'Too many stories … where do you start?' he said. 'People are being hurt here every day.'

Tom began his submission with a story of neglect. A man at his supported accommodation facility had mobility issues. One day, staff strapped him to a standing machine and left him there, alone. Outside the lawns were being mown loudly. But over the top of that noise, Tom could hear the man screaming.

Tom ran into the man's unit and found him alone, still strapped to the machine but nearly on the ground. Tom struggled to lift him and put the standing machine level again. He did his best to straighten him out and settle him down, but the man was screaming in pain the whole time.

Later the ambulance came and took the man to hospital. Doctors confirmed that both his legs had broken as a result of standing and not being able to hold his own weight up.

Tom told us he complained to various departments, commissions and tribunals but 'outcome, nothing'. The person responsible for the neglect and injury was away from work for a couple of weeks and returned 'with nothing to say about it'.

Telling us about another tenant, Tom said:

> They left her to live in conditions that were worse than a pig sty. They were taking about $100,000 from her funding every year, and not looking after her. It broke my heart.

He also told us:

> Another guy has paid near on $100,000 per year for over a decade, close to a million dollars funding. This person can walk ten metres or more fairly easily. But in the ten years I have lived here for, he has never had any physio. So he has to live in a wheelchair. He always says to me, I wish I could walk. It's sad because I can't help him.

'There is a guy I know', Tom continued, 'from Afghanistan. And for a long while he couldn't speak English very well, and he hardly saw his support worker until he could speak English better.'

Tom said he tries to help his fellow residents where he can. Sometimes that means getting them simple things they need, like milk or toothpaste, or helping them to do something – all things the service provider is supposed to be doing but often doesn't.

On occasion, Tom said, he has also tried to help by making a complaint, but recently this has landed him in the criminal justice system.

Tom told us that he had complained to his service provider about the senior person responsible for services. The person Tom complained about called the police and told them he was scared of Tom. At the time, Tom couldn't walk or talk and had to write on a whiteboard to communicate. Tom received a four-year intervention order banning him from talking to the person or the service provider – effectively banning him from making complaints.

When the service provider was bought out by another large company, Tom emailed the secretary of this company telling them about what was going on in the facility. The company responded by calling the police and claiming Tom had breached the intervention order. Tom told us the service provider is applying for an extension of the order for another four years, which means he still won't be able to make his complaint:

> I am not allowed to talk to him or mention his name in an email. I am also not allowed to contact his employer about him ... I've tried so many times to get a contact person I can talk to involved in the management of the facility, but the only reply I've had was a visit from the local police about a possible breach of the ... Court Order.

At the time of contacting the Royal Commission, Tom was awaiting an upcoming court hearing about a breach of his order that carries a possible two-year jail sentence.

14. Public hearing 4: Health care and services for people with cognitive disability

Key points

- The main purpose of the Royal Commission’s fourth public hearing was to start inquiring into the important issue of health care and services for people with cognitive disability.
- Of particular importance was the question of whether there is systemic neglect of people with cognitive disability in the Australian health system.
- Thirty-eight witnesses gave evidence, including people with cognitive disability, their family members and support people, advocacy groups, experts and representatives from the Australian and NSW government agencies.
- The Royal Commission explored several key themes, including how communication, information sharing, attitudes, assumptions and culture are essential for quality health care.
- We also heard evidence about the importance of preventative health care, dental health care, the transition from paediatric to adult health care and mental health care for people with cognitive disability.
- Several witnesses gave evidence about some key challenges in the health system for people with cognitive disability, including in non-metropolitan areas and for First Nations people, and about the importance of advocacy.
- The Royal Commission also heard evidence about the importance of education and training, and of the need for improvements in data collection to improve health outcomes.
- Based on the evidence, we found there has been and continues to be systemic neglect of people with cognitive disability in the health system.
- From Public hearing 4, the Royal Commission has identified areas for further inquiry. We will:
    - examine the impact of attitudes, assumptions and culture, and how that impact can be reduced or eliminated
    - ask the Australian, state and territory government health departments to conduct reviews on several issues
    - investigate barriers to adequate health care for people with cognitive disability
    - consider how training and educating health professionals could result in better outcomes for people with disability, and request information from state and territory governments on health care initiatives directed towards people with cognitive disability.

Introduction

The Royal Commission held Public hearing 4: Health care and services for people with cognitive disability, from 18 to 28 February 2020 in the Novotel Sydney Olympic Park Hotel. It was the first of our hearings to inquire into and examine health issues for people with disability. The purpose of the hearing was to examine the health care and services provided to people with cognitive disability in Australia and to determine whether this group of people is subjected to systemic neglect.

The themes and issues examined at this public hearing have also been raised with the Royal Commission through submissions, responses to issues papers, research and community engagement. Chapter 17, ‘Emerging themes and key issues’ provides a more detailed discussion of the emerging themes and key issues raised in the inquiry so far.

During Public hearing 4 we heard evidence from 38 witnesses. More than 500 documents and videos were tendered by Counsel Assisting the Royal Commission and accepted into evidence.

The witnesses included people whose health care experiences occurred in a number of different Australian states. Similarly, the expert witnesses described the health care challenges faced by people with cognitive disability around Australia. We also heard evidence about the health system operating in New South Wales and the initiatives that have been introduced in that state and nationally to try to improve health care and services for people with intellectual disability and autism.

Much of the evidence presented during Public hearing 4 concerned the experiences of people with intellectual disability and people with autism, which together are in the broad category of cognitive disability. As described in the Glossary, cognitive disability arises from the interaction between a person with cognitive impairment and attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis with others. Cognitive impairment is an umbrella term to encompass actual or perceived differences in cognition, including concentration; processing, remembering or communicating information; learning; awareness; and/or decision-making.

People with cognitive disability may include, but are not limited to, people with intellectual disability, learning disability, dementia, autism or acquired brain injuries, and some people with autism.

We heard from one expert witness, Professor Julian Trollor, that around 1.8 per cent of the Australian population has an intellectual disability.[1]

We have published a detailed report on Public hearing 4, which is available on the Royal Commission website. This chapter is based on that hearing report but does not cover every issue discussed there. References in this chapter are to sections and paragraphs of the hearing report rather than to the evidence presented at the hearing. Detailed references to the evidence and more information about the witnesses can be found in the hearing report.[2]

Witnesses

The 38 witnesses at Public hearing 4 included people with cognitive disability, parents, siblings and support persons of people with cognitive disability, advocates, experts, medical professionals and representatives of government departments and agencies.

The witnesses can be divided into four broad categories:

- direct experience witnesses[3]
- witnesses from advocacy groups[4]
- medical expert witnesses[5]
- government witnesses.[6]

We recognise that some witnesses could be placed in more than one of these categories and others may not fit squarely within any one of them.

The witnesses with direct experience of disability included people with cognitive disability and parents, siblings and support persons of people with cognitive disability. They told us about their own or their family's experiences in the health system, their views on what quality health care does or should look like and about the barriers to quality health care they have faced. In some cases, parents and siblings told us about the premature death of a family member with disability or their experiences of serious adverse health outcomes. They also suggested changes to improve health care and services for people with cognitive disability.[7]

The witnesses from advocacy groups and other experts gave detailed accounts of the systemic barriers to good health for people with cognitive disability, including the particular barriers faced by First Nations people with disability. They also described the programs and initiatives that could help to improve health care and services for people with cognitive disability provided they are sufficiently funded and properly implemented. They told us about research that demonstrates the substantial health disparities between people with cognitive disability and the general population and, in particular, the substantial differences in life expectancy. They also made detailed suggestions for improvements to health care and services to meet the needs of people with cognitive disability.[8]

Representatives of NSW Health and the Australian Government Department of Health described how the health system operates and the services and initiatives developed for people with intellectual disability.[9] The NDIS Quality and Safeguards Commissioner (NDIS Commissioner) explained the role of the NDIS Quality and Safeguards Commission (NDIS Commission) in collecting data on the deaths of people with disability.[10]

Key themes

The following themes emerged from the evidence in Public hearing 4 and are discussed in this section:

- quality health care
- attitudes, assumptions and culture
- communication and information sharing
- health system challenges
- lifetime health care
- integration of the health and disability service sectors
- reduction of distress and trauma
- training and education of health professionals
- collection of data and research
- initiatives to improve health care.

Quality health care

Article 25 of the United Nations *Convention on the Rights of Persons with Disabilities* requires States Parties such as Australia to recognise that people with disability have the right to enjoy the highest attainable standard of health without discrimination on the basis of disability.[11] Among other things, this means that Australia is required to ensure that health professionals provide care of the same quality to people with disability as to people without disability, including on the basis of free and informed consent. Evidence during Public hearing 4 suggested that this standard has often not been met in Australia and that there have been and continue to be systemic problems in the provision of health care and services to people with cognitive disability.[12]

However, some witnesses described positive experiences in the health system. These included accounts of health care professionals demonstrating that they view their patients with cognitive disability as meriting care and attention at least equal to any other patient.[13] The Royal Commission is therefore not to be taken as concluding that the health system invariably fails to respond appropriately to the needs of people with cognitive disability.

Witnesses with direct experience, as well as experts and advocates, told us that a person-centred approach is fundamental to high-quality health care.[14] While a number of health care policies and directives state the relevant organisation is taking a person-centred approach, implementation for people with cognitive disability in particular requires flexibility and adjustments to standard procedures.

As it is for people without disability, a relationship of trust and confidence between a person with cognitive disability and the medical practitioners who provide them with care and treatment is very important.[15] Collaborative care planning between a person with cognitive disability, their support people and medical practitioners allows the person to exercise greater choice and control over their care and treatment.[16]

Good communication is also crucial to quality health care. An aspect of good communication is supporting people with cognitive disability to make informed decisions about their care and treatment. This requires allowing people to have enough time and support to process information and understand complicated problems. A number of witnesses stressed that medical practitioners should take the time to explain things to their patients and to talk them through procedures.[17] In some cases, direct verbal communication is not possible and it is necessary to find alternative ways to communicate with a patient. These include the use of a communication board or accessible resources such as Easy Read, or the assistance of the patient's advocate or support person.[18]

Being involved in decision-making is one aspect of being treated equally to other people and having choice and control. Witnesses said that without support, a person with intellectual disability might lose their decision-making rights informally or formally.[19]

Attitudes, assumptions and culture

Witnesses described the achievements of people with cognitive disability and their value to local communities.[20] Parents spoke about the considerable potential of their children with cognitive disability and the extent to which they were independent.[21] All the witnesses who had children or siblings with cognitive disability described them as much-loved, integral members of their families.[22]

Despite the richness and variety of the lives of people with cognitive disability, pervasive societal attitudes towards them can influence decision-making on their health care and treatment. For example, some health professionals may make assumptions about the quality of their lives or their value to society. These assumptions and attitudes can create serious barriers to people with cognitive disability obtaining access to high-quality health care and services.[23] The problem of devaluing people with disability can be compounded for First Nations people when it intersects with institutional racism and negative public stereotypes and prejudices.[24] This is discussed further in Chapter 18, 'First Nations people with disability'.

Several witnesses described how negative attitudes or assumptions affected them or their children from the moment their child's disability was detected, either during pregnancy or soon after birth.[25] Other witnesses described events or occasions where they felt that assumptions about the quality of life of their family member with cognitive disability, and negative attitudes about their value, had consequences on the health care or treatment provided to them.[26]

A recurring theme in the evidence was the prevalence of 'diagnostic overshadowing', where symptoms or behaviours are misattributed to a person's disability rather than to health problems or conditions unrelated to disability. Diagnostic overshadowing may be a consequence of insufficient education or training on cognitive disability and may also reflect an underlying culture in the health system in relation to people with disability.[27] It can have serious consequences, such as misdiagnoses or delayed diagnoses of serious medical conditions unrelated to cognitive disability.

Diagnostic overshadowing can also happen in disability accommodation, particularly residential care. Disability workers in these environments can sometimes misattribute certain behaviours to a person's disability rather than questioning whether the behaviours might indicate medical problems or conditions.[28]

The Royal Commission also heard from several parents and support people about occasions when they tried to discuss with health professionals their serious concerns about a person with cognitive disability's condition.[29] They said that doctors and other medical specialists often dismissed or ignored these concerns on the basis that they were 'just a mum', were overwrought or had no formal medical training.[30] This culture of devaluing the knowledge and experience of parents and support people can be compounded for First Nations people.[31]

Communication and information sharing

It is important that health professionals communicate directly with people with cognitive disability and not only with their parents or support people. Witnesses described health professionals both failing to explain to the person with cognitive disability what was happening and saying things in front of them that were inappropriate or unhelpful.[32] Health professionals can improve communication by listening carefully to people with cognitive disability, explaining clearly what is happening and asking short questions in plain English.[33]

Better communication between health professionals and people with cognitive disability was identified as essential to improving the accessibility of health services. Witnesses spoke of some health professionals lacking communication skills and being reluctant to acquire them or to learn about forms of communication with, or the needs of, people with cognitive disability.[34]

We also heard evidence from parents, other family members and support people that on many occasions they felt they were not listened to by health professionals when raising concerns about the health needs of people with cognitive disability.[35] This was despite them having intimate understanding of the person with cognitive disability and being experts in their care.[36]

Several witnesses who have children with cognitive disability said that when health professionals respected, listened to and acknowledged them as holding important information, the health outcomes were much better for their children.[37]

Effective communication between health services and health professionals is also particularly important for patients with cognitive disability and complex needs. It is also critically important that complete and accurate records are transmitted between health services and health professionals, and provided to parents and support people.[38]

Some parents recounted that their children experienced a 'revolving door' of health professionals with no continuity of care.[39] They said they are required to 'start again' and go over the full medical history of their child with each new doctor they see.[40] In some cases, medical records for people with cognitive disability were inadequate, limited and omitted important information about the care to be provided to them.[41]

Expert witnesses agreed that information sharing and integrated care are essential for people with cognitive disability and complex health needs.[42] We heard about the My Health Record initiative, which has the potential to help achieve better coordination and integration of care.[43] However, some witnesses said the effectiveness of a My Health Record depends on information being documented, accurate and accessible.[44]

Health system challenges

While the Royal Commission heard that the Australian health care system compares well to other health systems around the world, there are systemic challenges that can adversely affect health outcomes for people with cognitive disability.[45]

Health care in non-metropolitan areas

People with cognitive disability in non-metropolitan areas can experience additional barriers and disadvantage in accessing appropriate health care.[46] Some witnesses described difficulties accessing specialist health services or needing to travel long distances to do so.[47] These difficulties can particularly affect First Nations people with cognitive disability and people living in rural and remote areas.[48]

First Nations people with disability and the health system

We heard some evidence about the failure of the health system to provide adequate care for First Nations people with cognitive disability.[49] First Nations people with disability face cumulative forms of disadvantage, which are compounded when institutional prejudice manifests in health services. For example, research suggests that First Nations people with disability are routinely confronted with an underlying presumption from other people that they lack the capacity to look after their health needs.[50]

The importance of strong advocacy

A number of witnesses told the Royal Commission that strong advocacy is essential to ensure that people with cognitive disability are provided with high-quality health care.[51] This includes people with cognitive disability acting as their own advocates and developing the skills to do so. Parents can also play a central role as advocates for their children with cognitive disability, including by helping them to communicate with health professionals so that they can speak up for themselves and make their own decisions. People with cognitive disability who are unable to advocate strongly for themselves and who have no family capable of doing so often experience problems in navigating the health system.[52]

Sixteen parents gave evidence about their experiences as advocates for their children with cognitive disability.[53] Some of these parents described their advocacy as 'fighting' for their child's right to high-quality care and treatment.[54] Some recounted their experiences in advocating for the most basic and even life-sustaining treatment for their children.[55] Parents usually have extensive knowledge of their children's needs and preferences. For this reason, and also because of deficiencies in continuity and coordination of care in the health system, they may have to assume responsibility for the management of their child's health.[56]

For advocacy to be effective, parents need support, education and training. One witness said that despite being a doctor herself, on one occasion she felt unable to advocate adequately for her son on her own.[57] Advocating for a child's health takes a toll on many parents. At least two parents said they feared dying because there would be no-one to assume the role of advocating for their child.[58] Some parents told us that although navigating the health system for their children had been a challenge, they recognised that they had a level of privilege in their capacity to do so.[59] Many people with cognitive disability do not have the benefit of strong advocacy support from parents or other family members or supporters.[60] There is therefore a need for independent advocacy services for people with cognitive disability and their families to support them to navigate the health system.[61]

Lifetime health care

Preventative health care

Effective preventative health care can reduce the onset and/or severity of multiple health conditions for people with cognitive disability. The importance of effective preventative health care was highlighted in research conducted by experts who gave evidence at the hearing.[62]

Several witnesses emphasised the importance of regular health assessments and discussed the Comprehensive Health Assessment Program (CHAP), a tool that can be used to prompt health care and screening for people with intellectual disability.[63] The process of a health assessment empowers participants, including people with intellectual disability, their supporters, primary-care staff and general practitioners (GPs). The benefits include obtaining the health history in accessible form, initiating consultations for overall review, prompting GPs and primary-care staff to consider commonly missed or poorly managed conditions, and improving the integration of primary health care with disability support services. In practice, regular health assessments are often not conducted for people with intellectual disability. Some witnesses said that specific Medicare items were introduced for regular assessments without a clear implementation strategy.[64]

Dental health care

Oral health is also central to overall wellbeing. It is a ‘whole-of-life’ issue where everyone benefits from ongoing professional and preventative care and maintenance. Dental problems and gum disease is particularly common among people with intellectual disability, and poor oral health correlates with increased risk of several adverse health outcomes or events.[65]

Limited access to dental assessments and treatment is a significant barrier to oral health for people with cognitive disability. This is a particular concern for people with cognitive disability in supported accommodation settings. There are often long waiting times to see ‘special needs dentists’ and we heard that many dentists do not have adequate skills to properly treat people with cognitive disability.[66]

Transition from paediatric to adult health care

The transition from paediatric to adult health care for people with cognitive disability can pose particular challenges. While paediatricians may coordinate or case manage the medical care of children with cognitive disability and complex health care needs, when children transition to adult health care they encounter a shortage of both generalist physicians and doctors specialising in the care of people with cognitive disability. This can result in young people falling through service gaps and experiencing poorer health outcomes during the transition to adult care.[67]

Mental health care

People with cognitive disability experience higher rates of mental ill-health than the general population but face barriers to high-quality mental health care and support. Medical experts gave evidence that people with intellectual disability and autism experience high rates of mental health conditions, well above the rates experienced in the general population.[68] They also stated that there are very high rates of suicidal ideation experienced by people with autism.[69] Three parents described their difficulties in attempting to access effective mental health services for their children with cognitive disability.[70]

Initiatives have been introduced to improve mental health services, in particular for people with intellectual disability. At the time of the public hearing, NSW Health was in the process of establishing two state-wide tertiary intellectual disability and mental health hubs for adult, child and adolescent patients who have an intellectual disability and mental illness.[71] Expert witnesses expressed the view that substantial additional resources are required to ensure that the initiatives significantly improve mental health services for people with an intellectual disability and a mental illness.[72]

End-of-life care

One witness who is an experienced palliative care physician informed the Royal Commission about cases where patients with cognitive disability were, in her view, inappropriately referred for palliative care rather than offered other available medical treatment.[73] Another medical expert gave evidence that people with intellectual disability who require palliative care are not necessarily referred for that care.[74]

Integration of the health and disability service sectors

Quality health care and better health outcomes for people with cognitive disability not only require improvements to the health system itself, but also its better integration with the disability services sector.[75]

Because people with cognitive disability can have complex health care needs, coordination between disability and health services is particularly important. Despite the benefits of a holistic approach, few shared models of care between disability and health services are in place. This is a particular issue with oral health care, creating a need for more effective training and interdisciplinary communication tools to connect the oral health and disability sectors.[76]

One advocate suggested that the National Disability Insurance Agency (NDIA) should establish a system to include a health facilitation role in the funding of NDIS plans for people with complex health support needs.[77] He also expressed serious concern about the minimal coverage of health in the standards of the NDIS Commission.[78] Another witness commented on the detrimental effect of the NDIS on existing partnerships between health and disability services, and the need for more coordination between them.[79]

The Royal Commission also received evidence that the level of training and competence of disability service staff can be relevant to how well the disability and health sectors work together.[80] Disability support workers need to be given basic health training and education, so that they are supported to deliver quality services.[81]

Reduction of trauma and distress

Health procedures and treatment for people with cognitive disability can cause trauma and distress. The sensory environment can affect the behaviour and emotional state of a person with intellectual disability and/or autism. This may lead to distress-induced behaviours such as resisting treatment or attempting to remove medical devices. The consequences of such behaviour may be detrimental to the patient’s health. In some instances, staff or support people may respond by resorting to restrictive practices.[82]

Accumulated trauma through repeated distressing experiences in hospitals and other clinical settings can have implications for every aspect of life for people with cognitive disability. A number of witnesses spoke in particular about the unnecessary trauma caused by decisions to deny pain relief to a person with cognitive disability.[83]

Several witnesses told us that adjustments to procedures or environments could and should be implemented to minimise distress and trauma for people with cognitive disability accessing health services.[84] Familiarisation and preparation can be important means of reducing distress for a person with intellectual disability. The use of simple, picture-based resources such as 'social stories' are valuable in assisting people with cognitive disability to understand new environments and the types of procedures they may need to have. In some cases, pre-medication may be required for a person with cognitive disability to be able to receive medical treatment or undergo procedures without experiencing trauma.[85]

One medical expert expressed the view that it is viable for the health system to implement adjustments that are most frequently needed for people with intellectual disability, such as longer appointment times, appointments being booked at certain times of the day or the use of visual aids to overcome communication difficulties.[86]

Training and education of health professionals

Several witnesses stated that education and training are needed to overcome the problems associated with a lack of skills and knowledge of some health professionals who treat people with cognitive disability.[87] The education and training of health professionals are said to be central to ensuring that people with cognitive disability have the same opportunity to lead lives as long and healthy as people without cognitive disability.[88]

A strong theme from the evidence is the urgent need to change assumptions about, and attitudes towards, people with cognitive disability. Many witnesses told the Royal Commission that they believe health professionals need additional or different education or training so that health decisions are not informed by their perceptions, attitudes and assumptions about cognitive disability.[89]

Some witnesses who have children with intellectual disability told us that they make efforts to educate medical students and doctors by demonstrating that their children are not defined by their disability.[90] Many witnesses, including people with cognitive disability, also emphasised the importance of directly involving people with cognitive disability in educating and training health professionals.[91]

A second area of education and training concerns communication by health professionals with people with cognitive disability and their families and support people. As noted earlier, poor communication has a significant impact on access to quality health care for people with cognitive disability.[92]

Education and training also needs to fill gaps in knowledge about cognitive disability. If health professionals have significant gaps in their knowledge and understanding of people with cognitive disability, it is more likely that the diagnoses will be inaccurate and that the health care needs of people with cognitive disability will not be adequately met.[93]

The Royal Commission heard that better education and training should be embedded at all levels of theoretical study and clinical practice, from undergraduate study to practical training to continuing professional development. On this approach, education and training should apply across the health profession, from clerical and administrative staff to clinical health professionals. Medical experts also told us that programs of continuing education should incorporate mandatory content on cognitive disability.[94]

Collection of data and research

Sound policy initiatives can be formulated only if they are supported by evidence. Vigorous research and the systematic and comprehensive collection of data are critical to developing policies that will improve health outcomes for people with cognitive disability. Research and reliable data can expose unacceptable disparities in health outcomes; highlight the health needs of particular groups, such as people with cognitive disability; establish a solid foundation for advocates to advance reform proposals; and assist governments and other policymakers to evaluate health services and address deficiencies in the quality of health care.[95]

Evidence from Public hearing 4 illustrates the disparity between the life expectancy of people with cognitive disability and that of the general population. This is cause for significant concern and speaks to an ongoing critical neglect of the health care needs of people with cognitive disability.

Professor Trollor gave evidence that, based on an extrapolation from NSW data, he estimated that about 400 people with intellectual disability over the age of 20 die in Australia each year from preventable causes.[96] However, he stated that there has been a limited amount of research examining the cause of death among people with intellectual disability or among autistic populations in Australia.[97] He also pointed to a lack of a consistent method for tracking and publishing mortality data, which would detect gaps in care and care pathways and direct future health care spending.[98]

Despite much valuable research conducted in Australia, increased funding is needed to fill gaps in the available information on the health of people with cognitive disability. More funding is required to support targeted, comprehensive and reliable research into the health of people with intellectual disability and people on the autism spectrum.[99]

Government witnesses acknowledged limitations in data collection about the health of people with cognitive disability at a state and national level.[100] We heard about the draft National Roadmap for Improving Health Services for People with Intellectual Disability that is being developed by the Australian Government Department of Health, in collaboration with various experts and advocacy groups. We heard that an element of the draft roadmap recognises that research, data and measurement are key platforms for tracking the health outcomes of people with intellectual disability and assessing the efficacy of initiatives to improve them.[101] The draft roadmap recommends the building of a national data asset on the health of people with intellectual disability.[102]

Initiatives to improve health care

New South Wales initiatives

There has been much-needed progress in New South Wales in recent years with respect to health care and services for people with intellectual disability. The Royal Commission heard that New South Wales is more advanced than other Australian states and territories on initiatives to improve health care for people with intellectual disability.[103] At the same time, the evidence is clear that there is more to be done.[104]

For example, many witnesses referred to a document known as The Essentials.[105] This is a guide for public health services to enhance their capability to work with people with intellectual disability. It was published in 2017 by the Intellectual Disability Network of the NSW Agency for Clinical Innovation. NSW Health told us that while data on the use of The Essentials is not collected at a state-wide level, the guide had been presented, demonstrated and discussed at many levels.[106] Several witnesses emphasised the need for greater use of the guide in New South Wales, as well as the need to launch it, or something similar, nationally.[107]

NSW Health has also had a Service Framework to Improve the Health Care of People with Intellectual Disability since July 2012. It has also set up and funded three specialist intellectual disability health teams for patients with complex and chronic health conditions. The Royal Commission heard that these teams were still being established at the time of Public hearing 4 and that their work must be reported against indicators to ensure that the model leads to meaningful outcomes and reduces avoidable health gaps for people with intellectual disability.[108]

As noted, NSW Health is also in the process of establishing two state-wide tertiary intellectual disability and mental health hubs. While there has been some progress on mental health care for people with intellectual disability in the state, the actions for people with intellectual disability set out in Living Well: A Strategic Plan for Mental Health in NSW 2014–2024 have not been fully implemented.[109]

Australian Government initiatives

One advocate informed the Royal Commission that the whole mainstream health system in Australia needs to lift its capacity to respond appropriately to people with intellectual disability.[110] At the same time, a network of specialised intellectual disability health services should be created, as has begun in New South Wales.[111]

Several witnesses discussed the national roundtable on the health of people with intellectual disability held in August 2019, which was organised by the Australian Government Department of Health.[112] Witnesses from the department described the roundtable and the draft National Roadmap for Improving Health Services for People with Intellectual Disability. We heard that a second roundtable was planned to further develop the draft roadmap, and that state and territory government representatives were invited to attend. However, we understand that this was postponed due to the COVID-19 pandemic.[113]

The Royal Commission heard about the ‘key elements’ of the draft roadmap and that funding these elements are decisions for the Australian, state and territory governments and relevant non-government organisations.[114] We also heard from experts and advocates that while they believe the draft roadmap is extremely important, they have concerns that it does not respond urgently enough to the deficits in health care and systemic shortcomings in the health and disability systems.[115]

The draft roadmap is focused on improving health care for people with intellectual disability and not people with cognitive disability more broadly. Despite the challenges experienced by people with autism in accessing and receiving health care described by a number of witnesses, there appears to be a dearth of national initiatives directed towards this group.[116]

Findings and areas for further inquiry

In our report of Public hearing 4 we did not make factual findings about specific incidents or about whether a particular person, agency or government had engaged in violence against, or abuse, neglect or exploitation of, a person with cognitive disability. We did, however, consider all the evidence received during and following the hearing, along with the submissions made by various parties afterwards. Based on that evidence, we found that there has been and continues to be systemic neglect of people with cognitive disability in the Australian health system.[117]

The Royal Commission is continuing to examine issues of health and health care affecting people with disability in Australia, including ways in which the systemic neglect of people with cognitive disability in the health system can be addressed. We set out below specific areas for further inquiry.

Quality health care

The Royal Commission will investigate the measures needed to enable people with cognitive disability, where possible, to make informed decisions about their care and treatment and to exercise choice and control in their interactions with the health system. Consideration will be given to:[118]

- the practical significance of a ‘person-centred approach’ of health professionals and institutions to people with cognitive disability and how such an approach can be implemented more widely
- the training and other measures required to encourage health professionals and staff to acquire the understanding and skills necessary to communicate clearly and effectively with people with cognitive disability
- how collaborative planning between people with cognitive disability and health professionals can be encouraged within the health system.

Attitudes, assumptions and culture

The Royal Commission will investigate the ways in which negative attitudes towards people with cognitive disability within the health system reflect outcomes and inflict distress. We will investigate:[119]

- the nature and extent of diagnostic overshadowing and how it can be reduced and, so far as feasible, eliminated
- the education and training necessary to enable health professionals and staff to better address negative attitudes and assumptions
- the changes required in the policies and practices of the authorities in each state and territory to ensure that the cause of death of a person with cognitive disability is accurately recorded and not wrongly attributed to the disability.

Communication and information sharing

In addition to investigating the means of improving communication at the three levels referred to above, the Royal Commission will request Commonwealth, state and territory health departments to:[120]

- undertake a review to identify their policies, practices and information relating to the health needs and care of people with cognitive disability
- assess whether the policies, practices and information are available in formats that can be readily accessed and understood by people with cognitive disability, their families and support persons
- report on actions that can and should be taken to make the policies, practices and information available in formats that are capable of being more readily accessed and understood by people with cognitive disability, their families and support persons.

In approximately 12 months the Royal Commission will:[121]

- seek an update from Commonwealth, state and territory health departments and primary health networks (PHNs) in relation to the reviews referred to above
- determine what recommendations should be made in relation to the issues raised by the reviews
- seek an update from the Commonwealth Department of Health (Commonwealth Health) as to the steps it has taken to improve the accessibility of My Health Records to people with cognitive disability and to promote the use of My Health Records by people with cognitive disability including through PHNs
- determine what recommendations it should make in light of the updates from the health departments.

Health system challenges

The Royal Commission will investigate:[122]

- the particular barriers limiting the access of people with cognitive disability living in regional, rural and remote areas to quality health care and the measures required to break down those barriers
- the multiple forms of disadvantage experienced by First Nations people with cognitive disability, particularly those living in regional, rural and remote areas
- the barriers to adequate health care faced by First Nations people with cognitive disability and the extent to which these barriers contribute to disparities in health outcomes for this group of people
- the culturally appropriate measures that should be taken to improve access to health services for First Nations people with cognitive disability in light of the multiple forms of disadvantage they experience
- the means by which people with cognitive disability, their families, carers and support persons can be supported in advocating for health care and treatment, including support for independent advocacy and self-advocacy.

The Royal Commission will also request the Commonwealth, state and territory governments to provide comments and advice on:[123]

- whether health facilitators or independent advocates for people with cognitive disability could be funded through the public health system
- how such a scheme could work, for example through services provided by GPs or through NDIS funding.

Considering the comments and advice received, the Royal Commission will consider what recommendations, if any, should be made.

Lifetime health care

Preventative health care

The Royal Commission will request Commonwealth Health to consider:[124]

- devising and implementing a strategy to encourage greater uptake of annual health assessments for people with cognitive disability both through primary health networks and key health services that reach people in First Nations and culturally and linguistically diverse communities, or who live in regional, rural and remote communities
- revising Medicare Benefits Schedule (MBS) item numbers applicable to comprehensive health assessments for people with intellectual disability and people with autism, and devising and implementing a strategy to encourage uptake of the revised MBS items.

In approximately 12 months the Royal Commission will:[125]

- seek an update from Commonwealth Health as to its consideration of the matters identified above
- after receiving the update, determine what recommendations the Royal Commission should make in relation to those matters.

Oral health

The Royal Commission will investigate:[126]

- the measures required to increase awareness among dentists, other health professionals and disability support workers of the oral health needs of people with cognitive disability
- the establishment of pathways to promote collaboration and coordination between disability support workers and dental services, as a means of improving the oral health of people with cognitive disability
- training programs to increase awareness among dentists and other health professionals of practices that reduce stress and anxiety among people with cognitive disability who seek or receive oral health care.

Transition to adult health care

The Royal Commission will investigate the measures required to establish a planned process for the transition of young people with cognitive disability into the adult health system, including a process for addressing sexual and reproductive health.[127]

Mental health

In approximately six months the Royal Commission will seek an update from Commonwealth Health concerning:[128]

- implementation of recommendations made in Accessible Mental Health Services For People with Intellectual Disability: A Guide For Providers and the additional measures Commonwealth Health proposes to take to ensure full implementation of those recommendations
- implementation of the Communiqué entitled ‘Recommendations from the National Roundtable on the Mental Health of People with Intellectual Disability 2018’,[129] including the resources that have been allocated for that purpose, including an assessment of additional measures and funding required to ensure full implementation of those recommendations
- further initiatives that are required at a national level to improve mental health care for people with autism.

In approximately six months the Royal Commission will seek an update from NSW Health concerning:[130]

- further implementation of Living Well: A Strategic Plan for Mental Health in NSW 2014–2024 in relation to the particular needs of people with cognitive disability (including people with autism)
- the functioning, resourcing and further roll-out of the Intellectual Disability/ Mental Health Tertiary Specialist Hubs
- action taken by NSW Health in light of the evidence at Public hearing 4 in relation to the mental health care needs of people with autism.

The Royal Commission will also request primary health networks to provide information concerning regional planning, integration and commissioning of mental health services for people with cognitive disability (including people with autism) at a local level, and the extent to which this planning work has involved the participation of people with cognitive disability.[131]

In light of responses and information received from Commonwealth Health, NSW Health and the primary health networks, the Royal Commission will determine what recommendations the Royal Commission should make on these issues.

Palliative care

The Royal Commission will investigate the inclusion of people with cognitive disability in the National Palliative Care Strategy and the measures needed to prevent referrals to palliative care in circumstances where medical treatment can and should be provided.[132]

Integration of health and disability services

The Royal Commission will investigate:[133]

- the means by which coordination can be achieved between health care and disability services to address the complex health needs of people with intellectual disability and people with autism
- the extent to which the individual funding model of the NDIS militates against coordination between the health care and disability sectors
- how violence against, and abuse, neglect and exploitation of, people with disability can be minimised through the quality and safeguards system of the NDIS Commission, including how that system can encourage and facilitate the integration of health care and disability support services.

The Royal Commission will also inquire into the practices and systems adopted in closed settings such as group homes that may limit people with cognitive disability from accessing appropriate health care.[134]

Reduction of distress and trauma

The Royal Commission will investigate adjustments that should be made to the hospital and clinical environment and to clinical procedures to minimise stress for people with cognitive disability consulting health professionals, undergoing tests, receiving treatment or being admitted to hospitals.[135]

Training and education of health professionals

The Royal Commission will consider how training and education of health professionals can result in better quality health care and outcomes for people with cognitive disability. In particular, the Royal Commission will investigate further:[136]

- the nature and content of training relating to cognitive disability currently provided to people studying to become health professionals or already practising as health professionals

- the extent to which training programs currently involve the participation of people with cognitive disability, their families, carers or support persons

- the effectiveness of education programs designed to improve communication between health professionals and people with cognitive disability and to address unconscious bias and negative assumptions held by health professionals about the value of lives led by people with cognitive disability

- the nature of training and education required to equip health professionals with the skills, knowledge and understanding necessary for the correct diagnosis of conditions experienced by people with cognitive disability and to avoid diagnostic overshadowing.

In light of these investigations, which may require a further short public hearing, the Royal Commission will determine the recommendations it should make on these matters.

Collection of data and research

In approximately six months the Royal Commission will seek an update from Commonwealth, state and territory health departments as to measures taken since Public hearing 4 to:[137]

- improve the collection and analysis of data relating to the health care and health needs of people with cognitive disability, including data collected on a national basis
- ensure that data is collected and presented in a form that can be usefully analysed by research centres and institutes for the purposes of research into the health needs and health care of people with cognitive disability
- provide ongoing funding to independent centres or institutes capable of conducting high quality research or data analysis relating to the health care and health needs of people with cognitive disability.

The Royal Commission will also request information from government and non-government agencies about their capacity to collate and publish accurate data on mortality rates and causes of death of people with cognitive disability, with a view to collecting and publishing data on a national basis.[138]

In light of the information received, the Royal Commission will determine the recommendations it should make in relation to data collection and research.

Initiatives to improve health care

The Royal Commission will request information from state and territory health departments, other than NSW Health, about:[139]

- whether they operate specialist health services for people with cognitive disability or have plans to create any such services
- whether they have resources similar to The Essentials used in New South Wales or could implement The Essentials or similar resources.

In approximately six months the Royal Commission will seek an update from NSW Health about:[140]

- the proposed timetable for evaluation of the specialist intellectual disability health teams
- progress in implementing a state-wide service model for specialist intellectual disability health teams and whether this model will cover all Local Health Districts (LHDs)
- plans to ensure that people with intellectual disability in non-metropolitan areas have access to the specialist intellectual disability health teams
- further measures that will be taken to ensure more comprehensive implementation of The Essentials.

The Royal Commission will request information from Commonwealth Health about the date set for the second National Roundtable after it was postponed due to the COVID-19 pandemic and progress that has been made in developing the draft roadmap.[141]

In approximately 12 months the Royal Commission will seek an update from Commonwealth Health about:[142]

- the postponed second National Roundtable and the measures Commonwealth Health has taken to implement the draft roadmap
- the steps it has taken to develop similar initiatives focused on the health and health care needs of people with autism.

In light of the information received, the Royal Commission will consider what recommendations should be made in relation to initiatives to improve health care and services for people with cognitive disability.

Endnotes

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4 Report of Public hearing 4, [99–124].
5 Report of Public hearing 4, [125–148].
6 Report of Public hearing 4, [149–171].
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11 *Convention on the Rights of Persons with Disabilities*, opened for signature 30 March 2007, 999 UNTS 3 (entered into force 3 May 2008), art 25.
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Gregory, Beth and Maya*

*** Names changed and some details removed to protect people's identities. Narrative based on a submission to the Royal Commission. Note that the submission and this narrative did not form any part of the evidence at the public hearing discussed in Chapter 14 of this report.**

Maya migrated to Australia in the 1990s and has been working in the Australian health system as a medical professional ever since. In her submission she said, 'The fact that I experienced challenges related to access within health all through my children's lives … is evidence that the system needs to make changes.'

Gregory and Beth, Maya's children, had a very severe form of a neuronal migratory disorder. Their illness meant they were unable to move independently and required wheelchairs; and they had low muscle tone, which also affected their breathing and their ability to swallow. Both children were non-verbal, but Maya believes they were cognitively more aware than they could communicate: 'Over time we managed to establish consistent communication with Gregory. He could make choices and respond to yes and no questions.'

Gregory was diagnosed 12 days after he was born, and his parents were told that he would die within a month. Even more devastating than being told he would die, said Maya, was being told that he was 'intellectually zero' and would never recognise his parents. Maya said that over time they discovered that Gregory and Beth were 'quite bright'.

Gregory did not die within a month; he lived into his early teens. Beth lived for more than three years. Most of the challenges Maya's family encountered with the health system occurred in the last few months of Gregory's life.

When a person can't communicate, or can't communicate in a traditional way, Maya said:

> their lives are viewed as having poorer quality and they are viewed as second class citizens … Many of our issues stemmed from communication breakdown or pre-judgement of a situation and decision-making that is not clinically based.

One example of this occurred towards the end of Gregory's life. Gregory had never had any urinary issues but suddenly he was having episodes that caused him great distress. He was groaning and crying – which was unusual because he was placid by nature and, having very weak vocal cords, rarely made a sound.

Maya and her husband knew something was wrong. Local clinicians reviewed Gregory and said he was dying. It was a few days later that Maya realised that Gregory's distress escalated whenever he was passing urine and that there was a white chalky discharge. The clinicians said that it was probably semen and was to be expected for a boy his age.

Maya insisted on a scan or ultrasound to check what was going on. The ultrasound showed renal stones. The doctor said that the stones were in a location that would not cause any pain, and that she would follow up in a few days. The next day Gregory was still in distress, so his parents took him to an emergency department.

The medical staff there talked to Gregory's primary medical contact, then told Maya and her husband to take Gregory home because he was dying.

Maya refused to go home while Gregory was in so much distress, and asked them to investigate the cause. 'I had to fight to have a request sent to the urology team to review the reason for his urinary retention.'

During his hospitalisation, Gregory's physical care needs were neglected. Maya said:

> We went home for one night and came back to find Gregory lying in a bed soaked with urine and faeces. It was devastating that my own colleagues did not look after Gregory. I shudder to think about what others with no links to the hospital faced.
>
> This is only a small part of the challenges we faced … We struggled to be heard and felt frustrated and angry about the lack of effort invested in helping us identify the reason for Gregory's distress.

Because Maya worked in the service where her family experienced most of the issues, she did not make a complaint. 'I did not have the strength to deal with the consequences and I was not confident about the outcome.'

She told us:

> I have really struggled in the bereavement period, because I feel that I let Gregory down. I feel that Gregory's pain and suffering at the end took away his passion for life and his will to live. Gregory and Beth were integral to our family and we miss them.

Quinn and Natalie*

*** Names changed and some details removed to protect people's identities. Narrative based on a submission to the Royal Commission. Note that the submission and this narrative did not form any part of the evidence at the public hearing discussed in Chapter 14 of this report.**

Natalie told us she is sick and tired of health professionals 'assessing someone's mental abilities by looking at them'. For example, a dentist once told her that it didn't matter if her son, Quinn, 'lost all his teeth … he had no mental capacity to care and that I was only concerned because it would bother me'.

Natalie told us that, since his teen years, Quinn has had problems accessing dental services. She explained how he needs general anaesthetic because his anxiety prevents him from staying still. He is autistic and has a cognitive disability, and he has difficulty allowing the dentist to get close to him.

When he was 15 years old Quinn was part of an NDIS trial which meant that, for the first time, he had a caseworker who helped Natalie find a dental service. As a single mother with another boy, the caseworker was a godsend. The problem, Natalie said, was the dental service could only be accessed every two years. If problems arose in between times, they were back to the drawing board.

Natalie said that's why Quinn ended up at the city dental hospital being told his teeth didn't matter; he didn't matter.

Quinn may not speak, 'but he certainly has a lot of understanding and emotions and feelings,' said Natalie. By the time they left the hospital 'he was melting down from the noise, the stress and the 4 hour trip there and back'.

In the end the dental hospital wouldn't admit him for dental work for three years.

Back home, with Quinn still in pain, Natalie went to the media. This triggered a change in policy in the local area and Quinn had his teeth fixed a year before he was scheduled. Everything was good for a few months until one of the fillings fell out. Natalie contacted the local service who did the original work, but they refused to help this time and suggested she have it fixed privately, which she could barely afford.

A friend recommended a private clinic in the city that did sleep dentistry as an alternative to general anaesthetic.

After a long trip and a long wait, Quinn was jittery and found it hard to sit still. Natalie said the anaesthetist reacted badly and inappropriately, yelling at Quinn and the nurses, saying he couldn't do his job if Quinn kept moving around. He also demanded Quinn's consent, which Quinn couldn't give. Natalie left in tears. Quinn left shaken and still missing a filling.

Natalie told us the clinic should have offered Quinn a sedative before his appointment, but the clinic was running behind schedule and forgot.

Natalie told us she is desperate. In addition to the media she has spoken to her state and federal politicians. They have offered some assistance, but she is often told about a service only to find out that the service isn't available or isn't suitable.

'What we have had to go through for dentistry I wouldn't wish on your worst enemy,' said Natalie.

Natalie would like to see better access to public dentistry and training for all medical professionals in how to treat patients with disabilities. Basic respect should be at the top of the list. She would also like to see sleep dentistry available in regional areas for people like Quinn.

15. Nature and extent of violence against, and abuse, neglect and exploitation of, people with disability

Key points

- High quality data is important for developing good policy and holding governments and organisations to account. Without good data, it is not possible to know whether violence against, and abuse, neglect and exploitation of, people with disability is happening more often, or less often.
- The *Survey of Disability, Ageing and Carers* contains good data on the number of people with disability in Australia. In 2018, there were around 4.4 million people with disability, or about 18 per cent of the population. The percentage of people with disability is much higher among First Nations people. In 2018–19, more than one-third of First Nations people had disability.
- We do not have good data on the extent of violence against, or abuse, neglect and exploitation of, people with disability. Multiple previous reports and inquiries have noted the absence of this data, and governments and others have been told many times to improve their data collections. Data, however, remains limited. This is especially the case for data about groups of people who may be more vulnerable to violence, abuse, neglect and exploitation, such as children, people with communication disability, First Nations people, culturally and linguistically diverse people, and LGBTIQ+ people with disability.
- There is no public data on the extent of violence, abuse, neglect or exploitation experienced by people with disability in particular settings, such as schools, residential out-of-home care, the youth and criminal justice systems, specialist disability accommodation or segregated work environments.
- The data we do have is sourced from the Australian Bureau of Statistics *Personal Safety Survey* (last conducted in 2016) and the *National Aboriginal and Torres Strait Islander Health Survey* (last conducted in 2018–19). This data is limited to experiences of violence and only covers some people with disability. There is no data on neglect or exploitation.
- The available data suggests that in 2016, almost 2.4 million people with disability aged 18–64 years (almost two in three) had experienced violence in their lifetime. In a 12-month period, people with disability are twice as likely as people without disability to experience violence.
- First Nations people with disability experience high rates of violence. In a 12-month period, around 6 per cent of First Nations adults with disability experience physical violence. First Nations people with disability comprise 52 per cent of all First Nations victims of recent physical violence.

Introduction

Previous chapters have detailed how past inquiries, the media, organisations working for people with disability and others have documented the many ways that people with disability have experienced violence, abuse, neglect and exploitation. This Royal Commission has started to hear about these experiences through public hearings, submissions, community forums and private sessions.

A constant theme has been the need for reliable data.[1] Data on who has disability, and their experiences of violence, abuse, neglect and exploitation, helps identify the causes of this violence, abuse, neglect and exploitation and guide the design of programs and policies to prevent it. Data helps to monitor the effectiveness of these programs and policies, and can hold governments and organisations accountable for improving outcomes for people with disability.

There remains limited data on the experiences of people with disability of violence, abuse, neglect and exploitation. This data gap is especially marked for groups of people who may be more vulnerable to violence, abuse, neglect and exploitation, such as children, people with communication disability, First Nations people, culturally and linguistically diverse people, and LGBTIQ+ people with disability. There is also very little or no data on people with disability living in institutions, such as prisons or healthcare facilities, or who are homeless.

This chapter starts with a discussion of why good data is important. It details findings and recommendations from some previous inquiries that have called for data improvements. We discuss what data is available and what remains unknown.

Next, we describe what *is* known about the number of people with disability, as well as what is known about the number of people with disability who have experienced violence, abuse, neglect and exploitation. This chapter relies on existing data in this area. It does not use information from our public hearings, submissions, community forums or private sessions – other chapters of this report discuss this information.

The chapter ends with a discussion of the Royal Commission's future directions and areas of inquiry to fill key data gaps. This includes:

- examining the adequacy of data use at the NDIS Quality and Safeguards Commission (NDIS Commission)
- research to scope a prevalence study on the extent of violence, abuse, neglect and exploitation experienced by people with disability
- examining the ways that administrative data sources, such as the National Disability Data Asset, can be used to monitor changes in violence, abuse, neglect and exploitation over time.

We use data to understand complex problems

Why good data is important

> Why do statistics matter? Put simply, they are the evidence on which policies are built. They help to identify needs, set goals, and monitor progress. Without good statistics, the development process is blind – policymakers cannot learn from their mistakes, and the public cannot hold them accountable.[2]
>
> The World Bank, 2000

The concept of using statistics and data to inform policy is not new.[3] However, it has gained momentum in recent years as governments and others aim to use a 'common sense method' to tackle complex problems.[4]

Violence against, and abuse, neglect and exploitation of, people with disability is a complex problem. It has many causes and can be difficult to detect when it occurs. There is no single solution or 'silver bullet' to stop it from happening. Governments, organisations, advocacy groups and others must work together to prevent it. They must also work together to better identify it when it does occur, and to support victims, their families and supporters and the community to respond in appropriate ways.

Without high quality data, it is difficult for governments and organisations to plan policies and programs that will prevent violence against, and abuse, neglect and exploitation of, people with disability. Data is needed to set goals and measure success against these goals, and to allow others to hold governments and organisations accountable for delivering on these goals. Data helps track progress on important action plans, such as the National Disability Strategy, and whether the Australian Government is meeting its responsibilities under the United Nations *Convention on the Rights of Persons with Disabilities* (*CRPD*).

Without detailed data, it is not possible to understand whether a particular program or policy has had an impact for a specific group, such as women, young people, First Nations people, culturally and linguistically diverse communities, and LGBTIQ+ communities. And yet it is often these groups about whom we know least.

The call for better data is not new

Violence against, and abuse, neglect and exploitation of, people with disability is not a new problem. Chapter 1, 'Why this Royal Commission is needed', provides an overview of the history of violence against, and abuse, neglect and exploitation of people with disability. It also describes the determination of people with disability and their advocates to bring social change and establish this Royal Commission. Appendix B lists the many past inquiries that have addressed violence against, and abuse, neglect and exploitation of, people with disability, including many that have made recommendations to improve data collection.

For example, in 2013, the United Nations Committee on the Rights of Persons with Disabilities recommended the many steps Australia should take to meet its obligations under the *CRPD*.[5] This included developing nationally consistent measures for the collection and public reporting of data related to violence against, and abuse, exploitation and neglect of, people with disability.[6] In 2019, the same committee noted the persistence of data gaps and again recommended that they be addressed, especially as they relate to women, children and First Nations people with disability.[7]

In 2015, the Australian Parliament's Senate Community Affairs Reference Committee published a report on violence, abuse and neglect against people with disability in institutional and residential settings.[8] The report noted that there were 'no nationally consistent data sets available to describe the extent of violence, abuse and neglect of people with disability'.[9] The committee singled out the Australian Bureau of Statistics, noting that two of its main surveys – the *Survey of Disability, Ageing and Carers* and the *Personal Safety Survey* – did not include questions that enabled an understanding of the extent of violence, abuse or neglect against people with disability. The committee's concluding view was that it was:

> concerned with the lack of reliable statistical data available for policy development to eliminate violence, abuse and neglect of people with disability. The use of passive and active exclusion of people with disability from the statistical record of our country means that issues of violence, abuse and neglect continue to remain out-of-sight and out-of-mind.[10]

In recent years, Australia has made some changes to the way in which it collects and reports data on violence against and abuse of people with disability. For example, the *Personal Safety Survey* from 2016 included questions to identify people with disability and their type of disability. However, some groups the Senate Community Affairs Reference

Committee identified in 2015 are still not included in the survey.[11] These groups include people living in institutional settings and those who might require some form of communication support, such as some people with intellectual disability, some Deaf people, and some people from culturally and linguistically diverse backgrounds.

There remains no nationally consistent data on neglect or exploitation of people with disability. Sources may include information about neglect of people with disability, such as hospital admissions records. However, this data does not show which records relate to people with disability or is not detailed enough to form the basis for good policy. No sources of data compile information on exploitation of people with disability.

The Royal Commission is reviewing past inquiries and reports, to examine why recommendations for improved collection of data have not been followed (see Chapter 11, 'Research and policy'). This will help us understand how to better advise governments, organisations and others to collect, monitor, and publicly report data on violence against, and abuse, neglect and exploitation of, people with disability.

The following section describes what data is available, and its limitations for understanding the extent of violence, abuse, neglect and exploitation experienced by people with disability. As mentioned, we end this chapter with three options for addressing data gaps.

Data on disability

Australia collects good statistics on the number of people with disability

Australia collects high quality statistics on the number of people with disability in the population. The best available source is the Australian Bureau of Statistics *Survey of Disability, Ageing and Carers*. The survey is 'high quality' because it:

- is conducted frequently (every three years)
- is recent (last conducted in 2018)
- uses a detailed set of questions to determine whether a person has disability (166 questions, see 'How the Australian Bureau of Statistics defines disability' below)
- samples many people.

This means the survey results are a good measure of the number of people with disability in the general population. In 2018, the survey sampled 65,000 people, including almost 12,000 people who lived in 'cared accommodation'.[12] This expression refers to housing in a health service building, such as hospitals, aged care hostels, mental health facilities and group homes for people with disability.[13]

We have used the *Survey of Disability, Ageing and Carers* to estimate the number of people with disability in Australia (see 'What we know about the number of people with disability in Australia and the nature of their disability', later in this chapter).

How the Australian Bureau of Statistics defines disability

The Australian Bureau of Statistics defines disability as ‘any limitation, restriction or impairment which restricts everyday activities and has lasted, or is likely to last, for at least six months’.[14]

The Australian Bureau of Statistics does not directly ask a person whether they have disability.[15] Instead, it asks questions to determine whether the person needs assistance, or has difficulty with, or uses aids or equipment to perform, different types of activities.[16] These activities include self-care (such as showering, bathing or dressing), household chores, schooling and meal preparation. People who experience restrictions or limitations in these everyday activities are classified as a person with disability, and people who experience no restrictions or limitations are classified as a person without disability.[17]

Based on the answers to survey questions, the Australian Bureau of Statistics also identifies whether a person has ‘profound or severe’ disability.

According to the Australian Bureau of Statistics, a person with ‘profound or severe’ disability:[18]

- is unable to do, or always needs help with, self-care, mobility or communication or
- sometimes needs help with self-care or mobility but has difficulty understanding or communicating with others.

How the Australian Bureau of Statistics groups disability types

In addition to grouping people with disability based on the ‘severity’ of disability, the Australian Bureau of Statistics groups people according to whether the disability relates to the functioning of the mind or senses, or to anatomy or physiology.[19] These disability ‘types’ may refer to a single disability or a number of similar disabilities. The disability types used by the Australian Bureau of Statistics are described in Table 15.1, with examples of the kinds of impairments that restrict daily activities.[20]

Table 15.1: List of disability types used by the Australian Bureau of Statistics

Disability type	Examples of impairments that restrict daily activities
Physical	• Shortness of breath or breathing difficulties • Blackouts, seizures or loss of consciousness • Chronic or recurrent pain or discomfort • Incomplete use of arms or fingers
Sensory	• Loss of sight, not corrected by glasses or contact lenses • Loss of hearing where communication is restricted or an aid is used • Speech difficulties
Psychosocial	• Nervous or emotional conditions • Mental illness • Memory problems or periods of confusion • Social or behavioural difficulties
Intellectual	• Difficulty learning or understanding things
Head injury, stroke or acquired brain injury	• Head injury, stroke or other acquired brain injury with long-term effects
Other	• Any other long-term conditions or ailments that require treatment or medication, and still restrict everyday activities • Any other long-term conditions that restrict everyday activities.

Source: Australian Bureau of Statistics (2019).

Good data on disability for First Nations people

While First Nations people are included in the *Survey of Disability, Ageing and Carers*, we have used a different source to estimate the number of First Nations people with disability. This is the Australian Bureau of Statistics *National Aboriginal and Torres Strait Islander Health Survey*. We have used this survey because it included more First Nations people (nearly 11,000 in 2018–19) and was specifically designed for use with First Nations people. For example, all interviewers for this survey first participated in cultural awareness training to ensure they understood cultural considerations for specific communities. Where possible, interviewers were accompanied by local First Nations advisors to explain the purpose of the survey to participants, introduce the interviewers and help find residents who were not at home.[21]

We know less about disability for LGBTIQ+ communities

We have used the Australian Bureau of Statistics *General Social Survey* to estimate the number of gay, lesbian and bisexual people with disability. The *General Social Survey* collects information about people aged 15 years and over, and is the only national survey that collects information on both disability and sexual identity.[22] The survey was last conducted in 2014, and included almost 13,000 people.

In the *General Social Survey*, people are asked whether they identify as heterosexual, gay or lesbian, or bisexual. A small number of people responded they 'did not know' or said they identified as something 'other' than the options provided. These response options may give too narrow a picture of the number of LGBTIQ+ people with disability, because they do not include people who identify as transgender, or intersex, queer or questioning people.

The *General Social Survey* was not designed to measure the number of gay, lesbian and bisexual people with disability. Estimates from the *General Social Survey* should be interpreted as 'indicative' rather than precise.

Data on violence, abuse, neglect and exploitation

Limited national data on violence, abuse, neglect and exploitation

We reviewed the public data in Australia to understand what was available on people with disability and their experiences of violence, abuse, neglect and exploitation. We found that there was some data on violence and abuse, but none on neglect or exploitation.

The data on people with disability and their experiences of violence is from the Australian Bureau of Statistics *Personal Safety Survey*, which was last conducted in 2016. The survey collects information from men and women aged 18 years and over about their experiences of violence since age 15. More than 20,000 people completed the 2016 survey, including around 6600 people with disability.[23]

The scope of the *Personal Safety Survey* is broad. People completing the survey are asked about their current and past experiences of violence from an intimate partner, emotional abuse, stalking, sexual harassment and general feelings of safety.[24] They are also asked about their experiences of maltreatment before the age of 15. This includes sexual and physical abuse, and witnessing violence between a parent and the parent's partner.

While the *Personal Safety Survey* is a valuable source of data on experiences of violence and abuse for people with disability, it also has limitations:

- The survey excludes children and thus no national survey data is available on children with disability and their experiences of violence, abuse, neglect or exploitation.[25] While the survey excludes children, adults are asked about their experiences as children.
- The survey excludes people living in institutions such as prisons and aged care homes, and those experiencing homelessness.[26]
- The survey excludes people who cannot give their answers confidentially, privately or in English.[27]

  The survey included people with disability living in group homes, provided that they were able to complete the survey without the assistance of someone else.[28] Given that people living in group homes typically have 'extreme functional impairment or very high support needs',[29] it is likely that most were excluded from participating because they required support to complete the survey.

These factors mean that people with disability are more likely to be excluded from the *Personal Safety Survey* than people without disability.[30] People with communication disability, people from culturally and linguistically diverse backgrounds, and those with intellectual disability are even more likely to be excluded. Ironically, the groups of people who may be most vulnerable to abuse are the groups about whom we know the least.

The *Personal Safety Survey* has other limitations for understanding the extent of violence against and abuse of people with disability. The survey asks about types of violence and abuse that many people experience. These include physical and sexual violence, violence from a partner and emotional abuse from a partner. However, there is no data on types of violence that may be specific to people with disability, such as:[31]

- bullying and discriminating against people with disability because of their perceived vulnerability

- deliberately withholding or denying access to medical treatment or medication for people with disability, or preventing their access to aids that improve their functional capacity, such as wheelchairs or hearing aids
- exploiting or denying a person's control over their own body, such as forced or coerced sterilisation.

The data cannot tell us whether the violence reported is part of a pattern of abuse or has only happened once.[32] This detail is important, especially when we look at domestic and family violence, which often involves an ongoing pattern of behaviour aimed at controlling a partner or other family member's behaviour through fear, power and control.[33]

Finally, the survey identifies whether people have disability at the time of the interview, rather than when they experienced violence.[34] Because disability is more common as people age (see 'Disability is more common as people age', later in this chapter), estimates of the extent of violence for older people with disability are not reliable. We have confined the analysis of violence against people aged 65 years and over to incidents that occurred in the last 12 months.

Data is very limited for First Nations people's experiences of violence, abuse, neglect and exploitation

The *Personal Safety Survey* does not allow us to separate data on First Nations people with disability from data on non-Indigenous people with disability. However, we have identified two surveys that include information on First Nations people with disability and experiences of violence. Both are conducted by the Australian Bureau of Statistics.

These are the *National Aboriginal and Torres Strait Islander Social Survey*, which was last conducted in 2014–15, and the *National Aboriginal and Torres Strait Islander Health Survey* (described earlier), which was last conducted in 2018–19. We have used the health survey because it is more recent and includes most of the same measures of violence as the social survey.

The *National Aboriginal and Torres Strait Islander Health Survey* does not give a complete picture of First Nations people with disability and their experiences of violence, abuse, neglect and exploitation. Reasons for this include:[35]

- Children are not included in the survey, which therefore provides no data on violence, abuse, neglect or exploitation of First Nations children. This means we are not able to tell whether First Nations children with disability experience violence, abuse, neglect or exploitation at a significantly different rate than First Nations adults with disability. We also cannot tell whether First Nations children with disability experience violence, abuse, neglect or exploitation at higher rates than non-Indigenous children with disability.
- Questions on violence are limited to threats of physical violence or

deliberate acts of physical violence. The survey does not ask about violence by a person's partner, nor about sexual violence, emotional abuse, or neglect or exploitation. This means the data gives a particularly poor understanding of the experiences of First Nations women, because they are more prone to these experiences than First Nations men.[36]

- Questions on violence are limited to violence in the previous 12 months. There is no data on lifetime experiences of violence for First Nations people.
- Interviews were conducted face to face with a trained interviewer but not necessarily in private. People may have been less likely to tell the interviewer about experiences of violence by an intimate partner or family member if the offender was home at the time.

There is no data on violence, abuse, neglect or exploitation for other groups with disability

There is no publicly available and reliable data on experiences of violence, abuse, neglect or exploitation for culturally and linguistically diverse people with disability. While the *Personal Safety Survey* collects information that acts as a proxy for cultural and linguistic diversity, the number of people in the survey who are culturally and linguistically diverse and have disability is too small to produce reliable estimates.[37]

There is no publicly available data on experiences of violence, abuse, neglect or exploitation for LGBTIQ+ people with disability, or for groups of people with disability who may have different or additional support needs. These groups include people granted a protection visa as refugees and humanitarian migrants,[38] people who are experiencing homelessness,[39] and children and young people in detention.[40]

There is no public data on the extent of violence, abuse, neglect or exploitation experienced by people with disability in particular settings, such as schools, residential out-of-home care, the youth and criminal justice systems, specialist disability accommodation or segregated work environments.[41]

We are therefore unsure whether these groups experience violence, abuse, neglect or exploitation more or less often than other people with disability. It remains difficult to prevent violence, abuse, neglect or exploitation, or better identify and support people who have experienced or are experiencing it, until this critical data gap is addressed.

What we know about the number of people with disability in Australia and the nature of their disability

There are 4.4 million people with disability in Australia

In 2018, there were around 4.4 million people with disability in Australia. That is 18 per cent of the Australian population, or nearly one in five people.[42] There were a similar number of men with disability as women with disability.

The percentage of the Australian population with disability has decreased over time, though the actual number of people with disability has increased due to population growth (see Table 15.2). In 2003, there were nearly 4 million people with disability, which was 20 per cent of the population. In 2018, the number of people with disability had increased by around 409,000, but the percentage of the population with disability shrank to less than 18 per cent, because the number of people without disability had grown more quickly.[43] The decreasing percentage of people with disability in the population may be due to a decline in the percentage of people with certain types of physical disability,[44] such as back problems.[45]

Table 15.2: Number and percentage of people with disability in Australia from 2003 to 2018

Year	Number of people with disability ('000')	Percentage of Australian population	Age-standardised percentage of disability [a]
2003	3958.3	20.0	19.8
2009	4026.2	18.5	17.7
2012	4234.2	18.5	17.4
2015	4290.1	18.3	17.0
2018	4367.2	17.7	16.1

[a] The 'reference' year for age-standardising is the estimated resident population at 30 June 2001.

Source: Australian Bureau of Statistics (2019).

The fourth column of Table 15.2 shows the 'age-standardised percentage of disability'. This shows what the percentage of people with disability in the population would be if our population *was not* ageing over time.

Disability is more common as people age

The older a person is, the more likely they will be a person with disability. In 2018, 3.7 per cent of children aged under five years (57,800 children) had disability, while 85 per cent of those aged 90 years or over (163,700 people) had disability.[46]

Table 15.3 shows the number of people with disability in Australia for three age groups: children (that is, aged under 18 years), adults aged 18 to 64 years, and adults aged 65 years and over.[47] The table also shows the percentage in each age group that have disability and the final column shows the number of people in that age group as a percentage of all people with disability. The bottom row shows the total number of people with disability.

Table 15.3: Number and percentage of people with disability by age group, 2018

Age group	Number of people with disability ('000')	Percentage of age group that has disability	Percentage of population with disability
Children aged under 18	453.7	8.2%	10.4%
Adults aged 18–64	1969.7	12.9%	45.1%
Older adults aged 65+	1941.5	49.6%	44.5%
Total	**4367.2**	**17.7%**	**100.0%**

Note: The numbers of people with disability in each age group do not add up to 4367.2 because the Australian Bureau of Statistics changes some numbers to protect the confidentiality of people completing the survey.

Source: Australian Bureau of Statistics (2019).

In 2018, around 450,000 children (aged under 18 years) had disability. This represents 8.2 per cent of all children, and 10.4 per cent of all people with disability.[48] There were more people with disability among older age groups: around 13 per cent of adults aged 18 to 64 years were people with disability, compared with almost 50 per cent of adults aged 65 years or over. More than two in five people with disability were aged over 65 years.

Children with disability

In 2018, more children with disability had intellectual disability than other disability types (see Table 15.4).[49] Almost one in 20 children had an intellectual disability, representing around 255,000 children. There were roughly equal numbers of children with a sensory (163,900 children) or psychosocial disability (166,100 children).

See Table 15.1 for examples of the kinds of impairments associated with each of the disability types listed below.

Table 15.4: Number and percentage of children (aged under 18 years) with disability by disability type, 2018

Disability type	Number of children aged under 18 with disability ('000')	Percentage of all children aged under 18
Physical	111.7	2.0%
Sensory	163.9	3.0%
Psychosocial	166.1	3.0%
Intellectual	255.0	4.6%
Head injury, stroke or acquired brain injury	11.4	0.2%
Other	99.7	1.8%
Total	**453.7**	**8.2%**

Note: People can experience more than one disability type at a time. This is why the numbers for each disability type do not equal the value in the 'Total' row and why the 'Percentage of all children aged under 18' column does not add up to 8.2 per cent.

Source: Australian Bureau of Statistics (2019).

Around 5 per cent of children in Australia (254,000 children) experience what the Australian Bureau of Statistics calls 'profound or severe' disability (see 'How the Australian Bureau of Statistics defines disability', earlier in this chapter).[50] As noted, this means a person:

- is unable to do, or always needs help with, self-care, mobility or communication or
- sometimes needs help with self-care or mobility but has difficulty understanding or communicating with others.

More children with psychosocial disability are considered to have ‘profound or severe’ disability than children with other disability types.[51] There are more boys with disability in Australia than girls with disability. The Australian Bureau of Statistics reports that boys are twice as likely as girls to have a sensory disability, and almost twice as likely to have an intellectual disability.[52]

Adults aged 18 to 64 with disability

In 2018, adults aged 18 to 64 years were more likely to have a physical disability than another disability type (see Table 15.5). Almost 1.3 million adults in this age group, or a little more than 8 per cent, had a physical disability.[53] More than 600,000 adults in this age group had a psychosocial disability, or nearly one in every 20. Around 470,000 adults aged 18 to 64 had ‘profound or severe’ disability, which is about 3 per cent of the adult population.

Table 15.5: Number and percentage of adults aged 18–64 years with disability by disability type, 2018

Disability type	Number of adults aged 18–64 with disability (‘000’)	Percentage of all adults aged 18–64
Physical	1283.6	8.4%
Sensory	403.2	2.6%
Psychosocial	614.1	4.0%
Intellectual	290.4	1.9%
Head injury, stroke or acquired brain injury	164.0	1.1%
Other	901.2	5.9%
Total	**1969.7**	**12.9%**

Note: People can experience more than one disability type at a time. This is why the numbers for each disability type do not equal the value in the ‘Total’ row, and why the ‘Percentage of all adults aged 18–64’ column for each disability type does not add up to 12.9 per cent.

Source: Australian Bureau of Statistics (2019).

Among adults aged 18 to 64 years, the number of people with ‘profound or severe’ disability varied by disability type, as it does for children. Around half of all adults in this age group with intellectual disability and 40 per cent of people with psychosocial disability had ‘profound or severe’ disability, compared with around 30 per cent of people with physical disability.[54] Around one-third of adults in this age category with a sensory disability had ‘profound or severe’ disability.

Older adults with disability

Like adults aged 18 to 64 years, adults aged 65 years and over are more likely to have a physical disability than another disability type (see Table 15.6).[55] However, the percentage of people with physical disability is much higher for people in this older age category. In 2018, more than one-third of all adults aged 65 years or over had a physical disability.[56] Around one-quarter of all people in this age category, or nearly 1 million people, had a sensory disability.

Table 15.6: Number and percentage of adults aged 65 and over with disability by disability type, 2018

Disability type	Number of adults aged 65+ with disability ('000')	Percentage of all adults aged 65+
Physical	1385.4	35.4%
Sensory	968.5	24.8%
Psychosocial	356.8	9.1%
Intellectual	203.0	5.2%
Head injury, stroke or acquired brain injury	147.5	3.8%
Other	842.5	21.5%
Total	**1941.5**	**49.6%**

Note: People can experience more than one disability type at a time. This is why the numbers for each disability type do not equal the value in the 'Total' row, and why the 'Percentage of all adults aged 65+' column for each disability type does not add up to 49.6 per cent.

Source: Australian Bureau of Statistics (2019).

The percentage of people experiencing 'profound or severe' disability increases sharply with age. Almost one in five adults aged 65 years and over, or nearly 690,000 people, had 'profound or severe' disability, compared with only 3 per cent of adults aged 18 to 64 years.[57] Similar to other age groups, the number of people aged 65 years and over with 'profound or severe' disability varied by disability type. Around 80 per cent of older adults with intellectual disability or psychosocial disability had 'profound or severe' disability, compared with 44 per cent of older adults with physical disability and 38 per cent of older adults with sensory disability.[58]

Most older people with disability live in private homes, not aged care

The Royal Commission into Aged Care Quality and Safety is examining the quality of aged care services provided to Australians, including the extent of mistreatment and all forms of abuse experienced by people accessing aged care services.[59]

Most people living in aged care have disability.[60] However, most people with disability, including most adults aged 65 years or over, do not live in aged care.[61] According to the Australian Bureau of Statistics *Survey of Disability, Ageing and Carers*, around 9 per cent of people with disability aged over 65 years lived in 'cared accommodation' such as an aged care facility, while 91 per cent lived in a private dwelling, including a self-care residence in a retirement village.

We seek to avoid overlap with the work of the Royal Commission into Aged Care Quality and Safety, which is now due to submit its final report in February 2021. Our examination of violence against, or abuse, neglect and exploitation of, older people with disability will be informed by the findings and recommendations in that final report. Nevertheless, it is important that we describe what we know about the extent of violence, abuse, neglect and exploitation experienced by older people with disability who continue to live at home.

More than one-third of First Nations people have disability

In 2018–19, around 306,100 First Nations people were people with disability, representing 38 per cent of the First Nations population.[62] The percentage of First Nations people with disability is considerably higher than the percentage of people with disability in the general population (18 per cent).

In 2018–19, there were around 73,000 First Nations children with disability, which is more than one in five First Nations children (see Table 15.7).[63] Children accounted for almost one-quarter (24 per cent) of all First Nations people with disability. About 234,000 First Nations adults aged 18 years or over had disability, representing almost half of all First Nations adults, and 76 per cent of all First Nations people with disability.

The Australian Bureau of Statistics did not break down the data relating to First Nations adults with disability into separate age categories. We have separated statistics for First Nations people with disability into two groups (children and adults), rather than three groups (children, adults and older adults) as we have done for the general population.

Table 15.7: Number and percentage of First Nations people with disability by age group, 2018–19

Age group	Number of First Nations people with disability ('000')	Percentage of First Nations population	Percentage of First Nations population with disability
Children (aged under 18)	73.0	22.3%	23.9%
Adults (aged 18+)	233.6	48.1%	76.4%
Total	**306.1**	**37.6%**	**100.0%**

Note: The numbers for each age group of First Nations people with disability do not add up to 306.1 in the 'Total' row because the Australian Bureau of Statistics changes some numbers to protect the confidentiality of people completing the survey.

Source: Australian Bureau of Statistics (2019).

First Nations children

The percentage of First Nations children with disability was higher for boys (26 per cent) than for girls (18 per cent).[64] Around 21,000 First Nations children had 'profound or severe' disability, which is around 6 per cent of all First Nations children.[65]

The most common disability type among First Nations children was sensory disability (see Table 15.8).[66] Nearly 40,000 First Nations children (12 per cent) had a sensory disability. Around 9 per cent of First Nations children had an intellectual disability and 5 per cent had physical disability.

Table 15.8: Number and percentage of First Nations children with disability by disability type, 2018–19

Disability type	Number of First Nations children with disability ('000')	Percentage of all First Nations children
Sensory	38.7	11.8%
Intellectual	29.0	8.8%
Physical	15.5	4.7%
Psychosocial	13.4	4.1%
Head injury, stroke or acquired brain injury	0.7[a]	0.2%[a]
Other	13.2	4.0%
Total	**73.0**	**22.3%**

[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 numbers for each disability type do not equal the value in the 'Total' row, and why the 'Percentage of all First Nations children' column for each disability type does not add up to 22.3 per cent.

Source: Australian Bureau of Statistics (2019).

First Nations adults

The number of First Nations men with disability is similar to the number of First Nations women with disability (both around 48 per cent).[67] Around one in 10 First Nations adults have 'profound or severe' disability (45,000 adults).[68] The most common disability type among First Nations adults is physical disability (see Table 15.9).[69] Around 30 per cent, or 150,000, First Nations adults have a physical disability. Almost one-quarter have a sensory disability, and one in 10 have a psychosocial disability.

Table 15.9: Number and percentage of First Nations adults with disability by disability type, 2018–19

Disability type	Number of First Nations adults with disability ('000')	Percentage of all First Nations adults
Physical	150.4	30.9%
Sensory	112.0	23.0%
Psychosocial	53.6	11.0%
Intellectual	40.3	8.3%
Head injury, stroke or acquired brain injury	8.5	1.7%
Other	72.4	14.9%
Total	**233.6**	**48.0%**

Note: People can experience more than one disability type at a time. This is why the numbers for each disability type do not equal the value in the 'Total' row and why the 'Percentage of all First Nations adults' column for each disability type does not add up to 48 per cent.

Source: Australian Bureau of Statistics (2019).

Counting the number of culturally and linguistically diverse people with disability is difficult

No agreed definition of 'culturally and linguistically diverse'

'Cultural and linguistic diversity' is an expression that is difficult to define.[70] Researchers tend to use the expression to describe communities for whom English is not the main language or whose cultural norms differ from the wider community.[71] The breadth of this description makes it hard to measure how many people with disability also identify as culturally and linguistically diverse.

The data we have presented in this chapter follows advice from the Australian Bureau of Statistics, which identifies people with disability as culturally or linguistically diverse if they:[72]

- were born outside of Australia in a country that is not a 'main English-speaking country' (Canada, New Zealand, Republic of Ireland, South Africa, United Kingdom, United States of America)
- speak a language other than English at home (including Auslan)
- speak English 'not well' or 'not well at all'.

The number of people with disability who are culturally and linguistically diverse may be greater than shown in the data below because the three criteria identified in the previous paragraph do not necessarily indicate whether someone feels or identifies as culturally or linguistically diverse.

People born in a country where English is not the main spoken language

In 2018, around 643,000 people with disability were born in a country that was not a 'main English-speaking country'.[73] This is around 2.6 per cent of the Australian population and almost 15 per cent of all people with disability. More than one in five people (21 per cent) who were born in a country where English was not the main language have disability.

The majority of people with disability who were born in a country where English was not the main language (60 per cent) were aged over 65 years. A large group were adults aged 18 to 64 years (39 per cent), but very few were children, that is, aged under 18 years (1 per cent).

People who speak a language other than English at home

In 2018, around 345,500 people with disability spoke a language other than English at home.[74] This is around 1.4 per cent of the Australian population and 8 per cent of people with disability. More than one in 10 people who speak a language other than English at home (11 per cent) have disability.

Similar to people born in a country where English was not the main language, the majority of people with disability who spoke a language other than English at home were aged over 65 years (56 per cent). A large group were adults aged 18 to 64 years (41 per cent), but only a few were aged under 18 years (3 per cent).

The 'people who speak a language other than English at home' category includes people in the Deaf community who use Auslan at home. In 2016, the *Census of Population and Housing* estimated that around 11,700 people used sign language at home, the majority of whom (87 per cent) used Auslan.[75] While not all people who use Auslan at home will have disability, many in the Deaf community identify as culturally and linguistically diverse.[76]

People who do not speak English well

In 2018, around 136,500 people with disability spoke English 'not well' or 'not at all'.[77] This is around 0.6 per cent of the Australian population and 3 per cent of people with disability. One-quarter of people who do not speak English well (25 per cent) have disability. The group of people who spoke English 'not well' or 'not at all' did not include people who had difficulty speaking English due to their disability type (for example, a communication disability).

Most people with disability who spoke English 'not well' or 'not at all' were older adults, that is, aged 65 years or over (73 per cent). One in four were adults aged 18 to 64 years (27 per cent) and less than 1 per cent were children, that is, aged under 18 years.

These numbers probably underestimate the number of people with disability who do not speak English well. When a person does not speak English well, the Australian Bureau of Statistics speaks to someone else on their behalf. If no one is available or able to speak on their behalf, that person and household may not be included in the survey.

Combining data on these three groups

Looking at these three groups together, the data suggests there are around 136,000 people with disability who were born in a country where English was not the main language *and* who speak a language other than English at home *and* do not speak English well or at all.[78] This is around 0.6 per cent of the Australian population and around 3 per cent of people with disability. More than one in four people who were born in a non-English speaking country *and* speak a language other than English at home *and* do not speak English well or at all have disability (27 per cent).

The age distribution of people with disability who were born in a country where English was not the main language *and* speak a language other than English at home *and* do not speak English well or at all mirrored the age distribution for people who do not speak English well or at all. Most were adults aged 65 years or over (71 per cent), around one in four were adults aged 18 to 64 years (27 per cent), and less than 1 per cent were children, that is, aged under 18 years.

There is little information about LGBTIQ+ people with disability

Little information is available on the number of lesbian, gay, bisexual, transgender, intersex and queer (LGBTIQ+) people with disability. The available data suggests that less than 1 per cent of the Australian population are gay, lesbian or bisexual and have disability.[79] This is around 3 per cent of people with disability and 23 per cent of all people who identify as gay, lesbian or bisexual, but these numbers probably underestimate the number of LGBTIQ+ people with disability. A small number of people selected 'other sexual identity' and 'don't know' in the Australian Bureau of Statistics 2014 *General Social Survey*, but these numbers were too unreliable to use.[80]

The data was not reliable enough to separate the numbers of gay, lesbian and bisexual people with disability into age groups.

India and Farah*

Farah is the mother of India – 'a bright, vivacious, caring young woman with a rare genetic condition called Turner syndrome'. Visible signs of Turner syndrome include a number of distinctive physical features and slow growth.

In her submission, Farah told us that when India was in her teens she needed to have a small operation at a children's hospital.

While she was prepped and waiting for surgery, 'one of the operating surgeons approached her and said straight off the bat, "So, do you go to a special school?"'

Farah said she and India 'were GOBSMACKED ... what a way to approach someone, anyone, let alone a person who was about to trust you with their life'.

'Not that it matters, but, as it stands, my daughter obtained an almost perfect score in year 12 and is currently studying for a PhD in Genetics.'

Farah said another incident occurred at the same hospital when India was in her mid-teens. A different surgeon was examining her. She was naked and vulnerable when he 'observed in a loud voice, over the top of her, "I'm not sure she has normal breast development"'.

Farah told us India 'cringed ... what a crushing situation for her at such an impressionable age'. Farah said she couldn't believe that these 'elite, trained surgeons' didn't understand words mattered.

She felt that India 'has already entered this world with the odds stacked against her and the doctors purporting to care for her, who we are meant to trust, are doing their darnedest to undermine her'.

Farah said she wants to know why these doctors are working in 'internationally significant hospitals' without knowing the 'consequence of their choice of words'.

She would like to see training programs for doctors that 'highlight best practice is not just about anatomy and physiology. That words matter. And the wrong words have life-long effects.'

Farah hopes that in future the medical profession will understand 'words count almost as much as medical procedure'.

*** Names changed and some details removed to protect people's identities. Narrative based on a submission to the Royal Commission.**

What we know about the nature and extent of violence, abuse, neglect and exploitation experienced by people with disability in Australia

We commissioned research to understand data gaps and analyse available data

We commissioned a group of researchers based at the Centre of Research Excellence in Disability and Health to review the data available on the extent of violence, abuse, neglect and exploitation experienced by people with disability in Australia. They confirmed that there was some data on the extent of violence and abuse, but no public data on the extent of neglect or exploitation of people with disability. The researchers concluded:

> the historical omission of people with disability from national data collections, and the lack of up-to-date analyses where data on violence and disability are available, means there is limited empirical evidence to inform governments, institutions and the community about best practices in prevention and response.[81]

The researchers determined that the Australian Bureau of Statistics *Personal Safety Survey* was the best available source of information on the extent of violence against people with disability (see 'Limited national data on violence, abuse, neglect and exploitation' earlier in this chapter for a description of this survey).

The researchers used a version of the *Personal Safety Survey* that is only available to people who are trained in statistics, and who complete training and undergo an approval process. They analysed the results from the survey using a statistical technique called 'survey weighting' so they could use the 20,000 survey responses to estimate the extent of violence for the wider Australian population. The researchers used another technique called 'age standardisation' to adjust for the different age profiles of people with disability and without.[82] This means that differences in the extent of violence experienced between people with disability and people without disability are more likely associated with disability than age.

We asked the Centre of Research Excellence in Disability and Health to examine the extent of violence, abuse, neglect and exploitation for:

- people with disability aged 18 to 64 years
- people with disability aged 65 years and over.

The analysis was separated in this way because disability is more common as people age.

As noted, the *Personal Safety Survey* identifies whether people have a disability at the time of the survey, rather than at the time they experienced violence. We asked the researchers to limit the analysis of people with disability aged 65 and over to recent experiences of violence only – that is, in the previous 12 months. In this way, we can be more confident that the person had disability at the time they experienced violence.

The researchers analysed whether people with disability were more likely to experience violence than people without disability. They considered several types of violence:

- **physical violence** – that is, the occurrence, attempt or threat of physical assault
- **sexual violence** – the occurrence, attempt or threat of sexual assault
- **partner violence** – any incident of sexual assault, sexual threat, physical assault or physical threat by an 'intimate partner'. An intimate partner is a current partner the person lives with, a previous partner the person lived with, or a current or previous boyfriend, girlfriend or date the person never lived with
- **partner emotional abuse** – when a current or previous partner behaves in a way that causes the person to feel afraid. These behaviours can include manipulation, control, isolation and intimidation. They are generally repeated behaviours, and include psychological, social, economic and verbal abuse
- **stalking** – behaving to someone in a way they believe is meant to cause them fear or distress, such as following or watching them, hanging around their home or workplace, or making unwanted contact with them by phone, mail, email, text messages or social media
- **violence** as a combination of all five forms of violence – that is, physical violence, sexual violence, partner violence, partner emotional abuse and stalking.

Unless otherwise indicated, the data reported in 'Experiences of violence for adults aged 18–64 with disability' and 'Experiences of violence for older adults aged 65 and over' below, is taken from the Centre of Research Excellence in Disability and Health reports. The full versions of these reports will be available on our website.

Experiences of violence for adults aged 18–64 with disability

Adults with disability are more likely to experience violence than adults without disability

Around 2.4 million adults aged 18–64 with disability have experienced violence in their lifetime. This is equal to 65 per cent of adults with disability in that age group having experienced physical or sexual violence, partner violence, partner emotional abuse or stalking in their lifetime, compared with 45 per cent of adults in that age group without disability. The difference between adults aged

18–64 with disability compared to adults in that age group without disability is even greater for recent experiences of violence. In a 12-month period, adults with disability are almost twice as likely as adults without disability to experience violence.

People with disability are more likely to experience physical violence than other types of violence. More than half of all adults aged 18–64 with disability (52 per cent, or around 1.9 million people) have experienced physical violence in their lifetime, compared with 34 per cent of adults in that age group without disability. Around one-third of people with disability (31 per cent) aged 18–64 have experienced emotional abuse, and one in five (21 per cent) have experienced sexual violence. Adults aged 18–64 with disability are also 2.4 times more likely to be stalked in a 12-month period than adults in that age group without disability.

Women with disability experience high rates of partner violence and sexual violence

The gender of an adult aged 18–64 with disability impacts their risk of experiencing different types of violence, as it does for people without disability. While all women are at higher risk of sexual violence than men, women aged 18–64 with disability are twice as likely to experience sexual violence in a 12-month period than women without disability in that age bracket. Around one-third of women aged 18–64 with disability (32 per cent, or 606,000 women) experience sexual violence in a year, compared with 16 per cent of women that age without disability.

Women aged 18–64 with disability are also at higher risk of partner violence than women without disability. More than one-third of women with disability (36 per cent) in this age group have experienced violence by a current or previous partner, compared with one in five women that age without disability (21 per cent).

Men aged 18–64 with disability are at increased risk of physical violence than men without disability in that age group. More than half of all men with disability (55 per cent) have experienced physical violence in their lifetime, compared with 40 per cent of men without disability. Men with disability are also at greater risk of sexual violence. Compared with men without disability, men aged 18–64 with disability are twice as likely to have experienced sexual violence.

Younger adults with disability experience high rates of violence

Younger adults with disability experience violence at much higher rates than older adults with disability. In a 12-month period, one in four people aged 18–29 years with disability (around 166,000 people) are estimated to experience violence, compared with around one in 10 people with disability aged 45–64 years.

Young adults with disability also experience violence at higher rates than young adults without disability. For instance, women aged 18–29 with disability are twice as likely to experience sexual violence as young women without disability.

Young adults with disability seem to be especially at risk of being stalked. In a 12-month period, they are three times more likely to experience stalking than adults aged 18–29 without disability.

The extent and nature of violence varies by disability type

Adults aged 18–64 with intellectual or psychosocial disability experience higher rates of all types of violence than adults in that age group with other disability types. In a 12-month period, around 28 per cent of people aged 18–64 with psychosocial disability and 24 per cent of people with cognitive disability experience violence. The real number could be higher, because people who were experiencing homelessness or who were in prison (who are known to experience higher rates of psychosocial disability) were not included in this survey.[83] In comparison, in a 12-month period around 20 per cent of people in this age bracket with sensory disability and 17 per cent of people with physical disability experience violence.

A person's gender and their disability type can combine to impact their risk of experiencing violence. One-half of women aged 18–64 with psychosocial (50 per cent) or cognitive (46 per cent) disability have experienced sexual violence in their lifetime. That is 334,000 women in total.

Compared with men with other disability types, men aged 18–64 with psychosocial disability also experience higher rates of emotional abuse and intimate partner violence. One-third of men in this age group with psychosocial disability experience emotional abuse in their lifetime, and one-quarter experience partner violence.

Violence rates are high for people with disability experiencing financial hardship

Adults aged 18–64 with disability are more likely than adults that age without disability to experience financial hardship. Financial hardship means having a cash flow problem in the last 12 months, such as not being able to pay electricity, gas or telephone bills, not being able to pay rent or a mortgage on time, going without meals, or being unable to cool or heat your home. People experiencing financial hardship are twice as likely to experience violence.

Financial hardship creates additional vulnerability for people with disability. Adults aged 18–64 with disability who experience financial hardship are three times more likely to experience violence than adults that age without disability who do not experience financial hardship.

Experiences of violence for older adults aged 65 and over

The Centre of Research Excellence in Disability and Health used the *Personal Safety Survey* to examine recent experiences of violence for people with disability aged 65 years and over. The *Personal Safety Survey* is limited in some important ways when it comes to understanding violence and abuse towards older people. First, the survey excludes people who live in 'cared accommodation' such as aged care homes. Older people with disability are more likely than young people to live in cared accommodation,[84] meaning older people with disability are likely to be under-represented in the *Personal Safety Survey* results. The Royal Commission into Aged Care Quality and Safety is examining abuse and neglect of older people in these settings.[85] The findings below relate to older people with disability who live in private dwellings, such as houses and apartments, self-contained retirement villages and residences in caravan parks.

Second, the *Personal Safety Survey* asks whether the person has disability at the time of the interview, rather than at the time of the violence. We have limited our analysis to 'recent' experiences of violence, that is, violence that occurred in the previous 12 months. This means we can be more confident that the person had disability at the time of the violence.

Third, the *Personal Safety Survey* does not distinguish between people who have had lifelong disability and those who have acquired disability from conditions associated with ageing. The factors placing these two groups at risk of violence are likely to be different.[86] People with lifelong disability may be at higher risk than people who have age-related disability, but we do not know.

Finally, the *Personal Safety Survey* does not ask about types of violence and abuse that older people may experience more often than other people. These include preventing or attempting to prevent access to funds, telecommunication or transport, and misuse of powers of attorney.[87]

Older people with disability experience violence at similar rates to people without disability

In a 12-month period, around 4 per cent of people with disability aged 65 years and over (or around 78,300 people) experience physical violence, sexual violence, intimate partner violence, emotional abuse and/or stalking. Similarly, 3.9 per cent of people aged 65 years and over without disability experienced violence during the same period. Older people with sensory disability experience slightly higher rates of violence than others (4.5 per cent).

Similar to women with disability aged 18–64 years, women with disability aged 65 years and over experience higher rates of violence than women without disability. In a 12-month period, 4.7 per cent of older women with disability (or around 48,000 women) experience violence, compared to 2.9 per cent of women aged 65 years and over without disability.

Rates of violence for older men are low, which means estimates for the extent of violence should be 'used with caution'.[88] The available data shows that older men with disability experience violence at a lower rate than men without disability, and at a lower rate than women with disability.

Violence is common for First Nations people with disability

There is no data on First Nations children with disability's experiences of violence, abuse, neglect or exploitation. The following analysis relates only to First Nations adults, aged 18 years and over.

First Nations adults with disability experience high rates of violence. In 2018–19, the *National Aboriginal and Torres Strait Islander Health Survey* found that around 15,100 First Nations adults with disability had experienced physical violence in the previous 12 months.[89] This equates to around 6 per cent of all First Nations adults with disability. Adults with disability accounted for more than half (52 per cent) of all First Nations people who experienced physical violence in the 12 months before the survey. The extent of physical violence among First Nations men and women with disability was roughly similar.[90]

Most often, and regardless of disability status, First Nations people experienced physical violence by a person they knew. Around 91 per cent of First Nations victims of physical violence knew the alleged perpetrator.[91] The data on the relationship of the alleged perpetrator to the victim was not reliable enough to use. On average, less than half of First Nations people with disability who experienced physical violence (40 per cent) reported the violence to police. There was a gender difference, with women more likely than men (55 per cent compared with 26 per cent) to report an incident of violence to police.[92]

Compared with First Nations adults without disability, First Nations adults with disability are less likely to feel safe. Less than half of First Nations people with disability (48 per cent) felt safe walking alone in their local area after dark, compared with 59 per cent of First Nations people without disability.[93]

Limited data on the experiences of children with disability

There is no national survey data on the extent of violence, abuse, neglect or exploitation experienced by children with disability. One of the only data sources on children's experiences of abuse and neglect is the number and percentage of children with disability in out-of-home care.[94] 'Out-of-home care' is when a child who cannot live with their family or current carers is placed with other carers by the government.

In 2018–19, this data was available for every state and territory except South Australia. For the jurisdictions that did collect data on disability, all except New South Wales had a high percentage where disability status was 'not stated'. This ranged from 25 per cent in Western Australia to 91 per cent in the Australian Capital Territory.[95] The remaining data, where disability status was recorded as 'disability' or 'no disability', covered 58 per cent of all children in out-of-home care in Australia.[96]

That data showed that, on average, 12 per cent of children in out-of-home care were reported as having disability. Data from the Australian Bureau of Statistics showed that children with disability aged under 18 years were 8 per cent of all children in Australia.[97] This suggests that children with disability are more likely to be in out-of-home care than children without disability.

There is no other data on children with disability in out-of-home care. Without more detailed data, it is not possible to know whether children with particular characteristics are more at risk of entering care, whether there are particular settings that place children with disability at risk, or whether children are more vulnerable to abuse after entering care.

Data on out-of-home care cannot give a true estimate of the extent of abuse and neglect of children with disability for a number of reasons:

- Out-of-home care data records the 'tip of the iceberg'. That is, it only records cases of abuse and neglect that authorities have been told about, that have been substantiated, and where statutory orders have been made to remove the child.
- Different states and territories define disability differently and collect information on disability in different ways. This means the percentage of children with disability across states and territories should not be compared.
- Out-of-home care data is not detailed enough to show whether some groups of children with disability, or some settings, are associated with higher rates of abuse or neglect.
- Some children in out-of-home care – including children with disability – were voluntarily placed into out-of-home care by their families or carers.[98] Data on children in out-of-home care may therefore include some children who have not experienced abuse or neglect.
- The data does not cover abuse of children with disability while they are in out-of-home care.

Summary of data gaps

Preventing violence against, and abuse, neglect and exploitation of, people with disability cannot be fully effective until we have better data. As described above:

- There is no national data on people with disability and their experiences of neglect and exploitation.
- The data on children with disability is limited to those in out-of-home care, which is inadequate for understanding children's experiences of violence, abuse, neglect and exploitation.
- There is no national data on violence against, and abuse, neglect and exploitation of, people with disability who live in institutions, such as prisons, or who are homeless.
- There is no data on First Nations people and their lifetime experiences of violence. There is no data on First Nations people and their experiences of neglect or exploitation. There is no data on First Nations children and their experiences of violence, abuse, neglect and exploitation.
- People who do not speak English well – or at all – including those with communication disability are often excluded from national surveys.
- There is no data on people with disability who are LGBTIQ+.
- There is no data on forms of violence that are specific to people with disability, such as bullying and discrimination, withholding access to medical treatments or medication,

and exploiting or denying a person's control over or ownership of their body.

- There is no way to tell whether people with disability's experiences of violence and abuse occur commonly and as part of a pattern, as in domestic and family violence, or are one-off events.

Future directions

Improving the availability of data on the nature and extent of violence, abuse, neglect and exploitation experienced by people with disability is a shared responsibility. Governments and organisations should not wait for the Royal Commission's final report and recommendations to begin addressing data gaps. Below, we detail six areas that we will focus on over the next two years. We welcome submissions and advice on other ways that data gaps could be filled.

The use of data at the NDIS Commission

When we review data on reports or incidents of violence against, or abuse, neglect or exploitation of, people with disability we are focusing on data held by the NDIS Commission. The NDIS Commission publicly released some data in its 2018–19 annual report,[99] and in its July to December 2019 activity report.[100] The following information and data is drawn from these reports.

The NDIS Commission regulates providers of services funded by the National Disability Insurance Scheme (NDIS). The NDIS Commission started operating on 1 July 2018, in New South Wales and South Australia only.[101] In July 2019, it began operating in all other states and territories, except for Western Australia, where it will commence in December 2020.[102]

Registered NDIS providers are required to notify the NDIS Commission of reportable incidents. Reportable incidents include:[103]

- the death of a person with disability
- the serious injury of a person with disability
- abuse or neglect of a person with disability
- unlawful sexual or physical contact with, or assault of, a person with disability
- sexual misconduct committed against, or in the presence of, a person with disability, including grooming a person with disability for sexual activity
- unauthorised restrictive practices (see the Glossary for a definition of restrictive practices).

The NDIS Commission data on reportable incidents could provide insights into the extent of violence against, and abuse, neglect and exploitation of, people with disability that occurs in the context of NDIS service provision. For now, the NDIS Commission advises that 'the number of reports received does not correlate to the number of actual instances of harm to a person with disability'.[104] The reasons for this include:

- The NDIS Commission will not operate on a national basis until 1 December 2020.
- The data relates to the number of reports lodged by service providers, rather than the number of alleged victims of harm. According to the NDIS Commission, reports can include multiple notifications of the same matter, as well as incidents that occurred but where harm to the person with disability was avoided.
- Providers are required to report every use of a restrictive practice as ‘unauthorised’ when there is no behaviour support plan in place. In some jurisdictions, at the time of writing this report, there was not yet a way to authorise restrictive practices.

The *National Disability Insurance Scheme Act 2013* (Cth) outlines the functions and powers of the NDIS Commission and restricts what information it can collect.[105] The data it collects therefore does not show the full picture of violence against, and abuse, neglect and exploitation of, people with disability. For example:

- Unregistered service providers are not required to report incidents or allegations of harm against a person with disability to the NDIS Commission.
- Incidents or allegations of violence, abuse, neglect or exploitation that occur outside of the context of NDIS supports and services are not classified as reportable incidents.
- Reports are not required for incidents or allegations involving people with disability who are not NDIS participants.

The available data shows that in the 18 months from the time the NDIS Commission started operating in July 2018 to December 2019, almost 74,000 reportable incidents took place. The vast majority of these (91 per cent) related to unauthorised use of restrictive practices. A breakdown by type of restrictive practice is available only for July to December 2019. This shows that most of the unauthorised use of restrictive practices related to the use of chemical (59 per cent) and environmental restraints (38 per cent). A small percentage (around 3 per cent) related to mechanical or physical restraints, or seclusion.

Around 4 per cent of the reportable incidents (2917 reports) in the 18-month period related to alleged abuse and neglect. Just over 2 per cent (1543 reports) related to known serious injury (including accidents) and 1.8 per cent (1318 reports) related to allegations of unlawful physical or sexual conduct. There were 785 reports of death (1.1 per cent, though again this may reflect multiple reports of the same death) and 355 allegations of sexual misconduct (0.5 per cent of all reportable incidents).

Of the 69,397 reportable incidents received by the NDIS Commission in the six months from July to December 2019, 1102 (1.6 per cent) were reported by providers to police. The NDIS Commission did not report how many in the previous year were reported to police.

The NDIS Commission data could be very useful to people with disability, service providers, researchers and others. We are looking carefully at how the agency collects, analyses and publishes data.

We will examine what the NDIS Commission is doing, and how effectively it is using data to uphold the rights and promote the health, safety and wellbeing of people with disability.

Barriers to using standard questions to identify people with disability

National survey data is valuable, but not collected often. For example, the *Personal Safety Survey* is conducted once every four years. Data is collected much more often by governments and organisations for the purposes of record keeping and administration ('administrative data'). Administrative data is collected by government agencies such as the police, health services and family and community services, as well as non-government community and specialist services, such as homelessness and domestic violence services. This data could be used to better track changes in violence against, and abuse, neglect and exploitation of, people with disability. With a few changes, the data could also show the extent to which people with disability interact with the criminal justice, child protection and health care systems.

Administrative data is most useful when different data sources use common ways of identifying people with disability. If all governments and organisations used the same questions to determine who is a person with disability, it would strengthen the quality of data on people with disability and enable better service delivery. In 2016, the Australian Institute of Health and Welfare (AIHW) developed a brief list of questions to identify people with disability or long-term health conditions who experience difficulties or need assistance in various areas of their life. The aim was for these questions to be used as a national standard for data collection so that information about people with disability is more consistent and easier to compare over time.

Implementation of the AIHW questions has been slow.[106] Some governments and organisations have no way of identifying people with disability in their data. We heard in our public hearing on health care, for example, that NSW Health does not identify people with cognitive or intellectual disability who receive health services,[107] and that it would be difficult to do so using current datasets.[108]

We intend to obtain information from governments and organisations collecting administrative data on what is stopping them from adopting standard questions. In particular, we are interested in whether it is because they are not required to do so or because of the costs involved. We will also ask whether there are other or better ways of identifying people with disability in a consistent manner.

The status of the National Disability Data Asset

The National Disability Data Asset was established by the Council of Australian Governments (COAG). In September 2019, COAG approved a pilot project to bring together data from the Australian Government, the National Disability Insurance Agency, and the New South Wales, Victorian, Queensland and South Australian governments.[109] COAG describes the purpose of the data asset as:

- helping to inform service choices by people with disability and their support people[110]
- allowing governments to better understand how people with disability are supported through services, payments and programs across multiple service systems.[111]

On 29 May 2020, the Prime Minister, the Hon Scott Morrison MP, announced that 'COAG is no more'.[112] We intend to obtain information from the Australian Government and state and territory governments about the future of this important work, and how the data asset can identify groups of people with disability who may be at a high risk of violence, abuse, neglect and exploitation.

Publishing data disaggregated by disability status

We know that government departments, service providers and others collect data on reports or incidents of violence against, and abuse, neglect or exploitation of, people with disability. However, this data is often not made public. When it is, it is often not disaggregated by disability status – that is, the data is not reported in a way that shows results separately for people with and without disability. It should be. We shall inquire about the plans of governments, service providers and others for making the data they collect on people with disability public. We also want to know how this can be done while protecting the confidentiality and privacy of the people and organisations involved.

Some data is disaggregated by disability status, but more could be done to show the experiences of groups of people with disability who may be at higher risk of violence, abuse, neglect or exploitation. For example, the recent *Child Protection Australia* report did show data for children in out-of-home care with disability, but did not disaggregate to show First Nations children.[113] We know that First Nations children are more likely to be in out-of-home care than non-Indigenous children.[114] Future releases of this report should disaggregate the disability data for First Nations and non-Indigenous children separately.

Research to scope a prevalence study

The Royal Commission has a number of research projects planned and underway to better understand the nature and extent of violence, abuse, neglect and exploitation experienced by people with disability. One of these projects is to scope how information on violence against, and abuse, neglect and exploitation of, people with disability can best be collected. In particular, we want to know how to define and measure neglect and exploitation. This is part of determining what resources and approach would be needed for a study on the extent of violence against, and abuse, neglect and exploitation of, people with disability, including in specific settings such as education and health.

The Royal Commission may not be able to conduct the study on the extent of violence, abuse, neglect and exploitation experienced by people with disability (a prevalence study) within the life of our inquiry. Such prevalence studies are very complex and sometimes need years of design and testing before collecting data.[115] For example, the first Australian study on the prevalence and characteristics of child abuse and neglect was awarded $2.3 million by the National Health and Medical Research Centre and will take four years to conduct, from 2019 to 2023.[116] Prevalence studies are even more complex when they try to include the experiences of people who have been excluded from previous studies, such as people with disability living in institutions.

We will ask governments, academics, service providers and others about ways to conduct ethical and methodologically robust research to understand the nature and extent of violence, abuse, neglect and exploitation experienced by people with disability.

Exploring how well recommendations from past inquiries and reviews have been followed

Our review of past inquiries shows that many have made recommendations on data (see ‘The call for better data is not new’ at the beginning of this chapter).

We intend to obtain information from governments and agencies that have been subject to recommendations to improve their data collections about why they have not done so. We want to understand the barriers to making changes, and why some recommendations are implemented while others are not. This will help us to ensure our own recommendations are clear and achievable.

Submissions and advice to guide our inquiry

We welcome submissions and advice from governments, organisations, academics, people with disability and others on how critical data gaps can be filled. We want to understand what else can be done to improve the availability, monitoring and reporting of data to better prevent and respond to violence against, and abuse, neglect and exploitation of, people with disability. Evidence-based policy is only possible with better data. It is only through data that policy makers can improve over time and be held to account.

Endnotes

1 In this chapter, ‘data’ is used in the singular as this is how most people use and understand the term.

2 The World Bank, *Development indicators*, report number 20372, March 2000, p vii.

3 Gary Banks, ‘Evidence-based policy making: What is it? How do we get it?’ ANU Public Lecture series, presented by ANZSOG, Productivity Commission, Canberra, February 2009, p 3.

4 Office of Best Practice Regulation, ‘From RIA to RIS – evidence-based policy in action’, Canberra, December 2019. <www.pmc.gov.au/news-centre/regulation/ria-ris-evidence-based-policy-action>

5 Committee on the Rights of Persons with Disabilities, *Concluding observations on the initial report of Australia*, *adopted by the Committee at its tenth session*, UN Doc CRPD/C/AUD/CO/1 (21 October 2013).

6 Committee on the Rights of Persons with Disabilities, *Concluding observations on the initial report of Australia*, *adopted by the Committee at its tenth session*, UN Doc CRPD/C/AUD/CO/1 (21 October 2013), p 7 [54].

7 Committee on the Rights of Persons with Disabilities, *Concluding observations on the combined second and third periodic reports of Australia*, 499th and 500th meetings, UN Doc CRPD/C/AUS/CO/2-3 (15 October 2019), [58] .

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Daisy and Palin*

> **He moves her arms and legs forcefully while getting dressed and undressed like he will break her bone. I've tried to calm him down and remind him that he can't do like that, he says 'it's not rough enough'.**

Palin is a support worker who has written to us about the husband and primary carer of one of his clients, Daisy. Daisy has multiple sclerosis and dementia, and Palin has been working with her at least once a week for more than a year. He's worried about the care Daisy receives the rest of the time from both her husband and the service provider.

Palin said in his submission that Daisy's husband is 'very rough and aggressive' with her. For example, she needs a hoist to get on her bed and into the shower chair and wheelchair. Palin said that her husband swings her so aggressively that she bumps into things and gets bruises.

When Palin told Daisy's husband that she had broken skin, rashes or blisters, he told him 'not to worry until it's infected'.

Palin is also concerned about the quality of service from the service provider. Daisy spends most of her time in one position, which means she gets pressure sores. These need proper cleaning, padding and ointments. But some support workers don't do this often enough. If Daisy has had bowel movements during the day, they just put a clean continence aid on without cleaning.

'I just came out of her house, when I got in her room it was smelling very bad and I could tell why,' Palin told us.

Palin said he has reported this to the service provider a number of times to no avail. He has also raised the issue with Daisy's husband, who said he 'couldn't care less' about Daisy's wellbeing:

> He yells at her and says it's her fault for being in the wheelchair, it's her fault that the nappies are not put on properly and the bedsheets are soiled, which gives extra work to him.

Palin would like to see aged care and disability care workers do emotional intelligence tests before they are appointed, especially those working in home care. 'I hope all the people regardless of their physical or mental conditions receive the treatment they deserve,' he said.

*** Names changed and some details removed to protect people's identities. Narrative based on a submission to the Royal Commission.**


Alastair McEwin AM
Commissioner, Disability Royal Commission

Part D: Emerging themes and our future direction

Part D of the interim report describes the theoretical approaches that frame our inquiry and the themes emerging from our work so far. It then sets out the Royal Commission's future direction.

Chapter 16, 'Our theoretical approaches' details the four theoretical approaches that come from our terms of reference and guide our work. They are human rights, disability theory, intersectionality and life course.

Chapter 17, 'Emerging themes and key issues' discusses the themes and key issues that have emerged in the first phase of our inquiry. Some themes and issues have been the subject of detailed evidence at public hearings. Others have been identified in submissions, responses to issues papers and from what we have heard through our community engagement activities.

Chapter 18, 'First Nations people with disability' outlines what we have heard about what it means to live as a First Nations person with disability in Australia. The chapter identifies key issues that we hoped to examine in public hearings during the first half of 2020, but which had to be postponed in March due to the COVID-19 pandemic. These issues will now be considered when we resume those hearings in August 2020.

Chapter 19, 'Our future direction' describes how the Royal Commission will build on the work we have done to date. It details how we will draw on what we learn through public hearings, submissions, community engagement, private sessions, research and policy work to deepen our understanding of the themes and key issues that have emerged and to develop recommendations to prevent and respond to violence against, and abuse, neglect and exploitation of, people with disability.

Content warnings

Please be aware that this report contains information that may be distressing to readers.

It includes accounts of violence against, and abuse, neglect and exploitation of, people with disability and references to suicide and self-harming behaviours.

In some first-hand accounts of violence, abuse, neglect and exploitation, people have told us of abusive or offensive language they have experienced or witnessed. As a result, some direct quotes in the report contain language that may be offensive to some people.

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

If you need support to deal with difficult feelings after reading this report, there are free services available to help you. Information about these services can be found at the beginning of this report (see page vi) and in Chapter 6, ‘Support for people engaging with the Royal Commission’.

16. Our theoretical approaches

Key points

- Four theoretical approaches guide our work: human rights, disability theory, intersectionality and life course. We use these approaches in response to the requirements of our terms of reference.
- Our work is informed by human rights principles. The United Nations *Convention on the Rights of Persons with Disabilities* sets out the rights of people with disability at an international level. We are developing an approach to realise those rights for people with disability in Australia.
- Disability is a concept that has changed over time. We use the insight of disability theorists to help us understand disability discrimination and disadvantage, and it will inform our recommendations.
- Experiences of violence, abuse, neglect and exploitation are multi-layered, influenced by the intersection of disability with a person's age, sex, gender, gender identity, sexual orientation, intersex status, ethnic origin and race.
- Events in one life stage can have profound consequences across a person's life. A life course approach helps us to see patterns where particular changes or events predict poor outcomes later in life, and then to make recommendations to change those patterns.

Introduction

Four main theoretical approaches inform the work of the Royal Commission. These approaches, which come from our terms of reference, are human rights, disability theory, intersectionality, and life course.[1] The Royal Commission draws on existing knowledge in these areas to develop an approach that helps us understand the forces that shape the lives of people with disability and make recommendations for lasting change. This chapter provides an overview of our understanding of each of these four approaches, and how we intend to use them in our work.

Our human rights approach is informed by the human rights frameworks developed in various United Nations conventions. We give special attention to the United Nations *Convention on the Rights of Persons with Disabilities* (*CRPD*), which has influenced disability policy globally and is explicitly recognised in our terms of reference.[2] Our understanding of disability draws on the various models and theories developed by academic theorists and disability advocates to show how social forces shape the experiences of people with disability.

The term ‘intersectionality’ refers to the interaction between different types of prejudice and oppression, such as ableism, racism, sexism, ageism or homophobia, which creates unique forms of disadvantage and discrimination.[3] Our approach to intersectionality is informed by the work of legal academics, social scientists and advocates. It responds to the requirement in our terms of reference to consider the multi-layered experiences of people with disability and the influences of age, sex, gender, gender identity, sexual orientation, intersex status, ethnic origin or race, as well as the particular experiences of First Nations people with disability and culturally and linguistically diverse people with disability.[4] The life course approach is taken from the social sciences. It helps us to understand individual pathways and trajectories in the context of larger social changes and trends. These approaches have been applied to the learning described in Part D, ‘Emerging themes and our future direction’.

Human rights

Our inquiry is framed by human rights. As discussed in Chapter 3, ‘Our terms of reference’, the Royal Commission’s terms of reference explicitly recognise the human rights of people with disability.[5] We therefore seek to apply an approach informed by human rights to our work.

How human rights are interpreted and applied in Australia differs depending on context. Australia does not have a federal charter or bill of rights that seeks to realise or implement Australia’s international human rights obligations. However, a number of jurisdictions, such as the Australian Capital Territory, Victoria and Queensland, have taken steps to translate some international human rights into law.[6]

At the international level, Australia has ratified the *CRPD*.[7] The *CRPD* sets out obligations for the Australian Government to undertake to ensure and promote the full realisation of all human rights and fundamental freedoms for all persons with disability, without discrimination of any kind on the basis of disability.[8] While the Australian Government has international legal obligations to realise the rights described in the *CRPD*, these obligations do not automatically apply in Australian law to give people rights they can enforce against governments and persons in Australian courts and tribunals. Some rights and obligations articulated in the *CRPD* are reflected in part in domestic Australian law, such as in the *Disability Discrimination Act 1992* (Cth) (which predated Australia's ratification of the *CRPD*).

Human rights play an important role beyond just imposing legal obligations on government. They reflect a set of values, such as the dignity, autonomy, freedom and equality of all people.[9] The *CRPD* articulates values and standards by which people with disability should be treated and informs community values and standards.

All multilateral international agreements are the product of negotiations and compromise by participating nations. International conventions tend to be drafted using rather general language that is often open to different interpretations.[10] The *CRPD*, although it recognises a wide range of rights of people with disability, is no exception.

As we note in Chapter 3, our terms of reference direct us to inquire into 'all forms of violence against, and abuse, neglect and exploitation of, people with disability, whatever the setting or context'.[11] They also instruct us to examine the role of governments, institutions and the community.[12] Our terms of reference therefore give this Royal Commission a mandate that goes beyond the obligations imposed on the Australian Government as a party to the *CRPD*. The mandate includes inquiring into what government at all levels, institutions, the community and individuals should do to prevent and protect people with disability from experiencing violence, abuse, neglect and exploitation.[13]

We are committed to developing and implementing an approach informed by human rights across our work. This applies both to how we carry out our work as an organisation and how we understand and analyse the impacts of laws, government policies, institutions and the community on the rights of people with disability. The approach will inform the recommendations to be included in our final report.

We aim to translate human rights into practical and sustainable policies and practices that change the values and standards the community expects to be upheld for people with disability.

Disability theory

The human rights framework set out in the *CRPD* draws on disability theory, which developed as a discrete intellectual movement alongside the disability rights movement in the second half of the 20th century.[14] Disability theory has tended to identify, analyse and propose models to understand the forces that shape the lives of people with disability.[15] The best known are the medical and the social models.[16] Others include the charity model,[17] cultural theory,[18] and social role valorisation (originally known as normalisation theory).[19] In the following section we provide a brief summary of each of these models and theories.[20]

The Royal Commission uses disability theory:

- to identify outdated and rejected (albeit still pervasive) models and theories of disability, such as the medical model and the charity model
- to understand the models and theories that motivate our work, including the social model and the cultural model
- to synthesise the ideas and theories that emphasise individual self-determination and the capability approach.

Disability and disability theory are evolving concepts that continue to develop over time.[21] Categorising disability theory is an aid to understanding the forces that shape the lives of people with disability but in reality, disability theorists interact with each other's work and the boundaries between models and theories can be blurred.[22]

The charity model

The charity model understands disability as a tragedy to be offset by giving.[23] Disability advocates say that charity, which is often motivated by pity, can mark people with disability as inferior.[24] Charity risks encouraging dependency and paternalism.[25] Paternalism is the assumption that people with disability (and First Nations people and other marginalised groups) need to be cared for and managed for their own good, despite their individual will and preferences.[26] Theorists say that paternalism is often subtle, in that it casts the oppressor in the role of protector.[27]

In Australia, social welfare programs have replaced many services once offered by charities (and private and public provision is now intermingled).[28] The fundamental purpose of social welfare is to provide reasonable resources to people who, for various reasons, cannot earn a liveable income or require additional support services.[29] Yet disability theorists and advocates say that people with disability who receive welfare and support services are often treated as lesser citizens or as a burden on the state, and are placed under increasing forms of supervision and control.[30] They argue that welfare services, whether government or non-government, are often delivered without the input of people with disability and so can produce dependency and hierarchies of power.[31] Power imbalances can result in violence, abuse, neglect and exploitation.[32]

Like many people without disability, many people with disability depend on welfare programs.[33] Researchers and advocates say that, rather than behaving as though they are delivering services to passive users, welfare providers should recognise that people with disability have expert knowledge in their own experience of disability.[34] People with disability can be included as co-producers and active and equal partners in the design and delivery of services.[35] Proponents say that co-production should include people with disability at all levels of service delivery, especially in leadership roles.[36] Co-production fulfils the principle of 'nothing about us without us', which is that no policy or practice should be developed or implemented without the leadership of and input from people with disability.[37]

The criticisms of the charity model do not mean that there is no role for charities or other welfare organisations to play in providing support to people with disability. However, the criticisms do mean that support should be provided in a manner that acknowledges and respects the autonomy, dignity and choices of people with disability, and accepts that people with disability must be consulted and have leadership roles in any programs.

The medical model

The disability rights movement has its theoretical origins in the distinction between the medical and social models of disability.[38] While medical diagnosis and treatment are important to the health and wellbeing of people with disability, the medical model as understood by most theorists treats disability as an individual defect to be eliminated, cured or hidden away.[39] Historically, this was apparent in the eugenics movement, which attempted to rid society of 'defective' humans, and in the segregation of people with disability in residential institutions.[40]

Medical diagnosis can result in disability being thought of as abnormality.[41] Disability theorists argue that diagnosis or classification of disability also gives medical and other professionals power and control over people's lives.[42] For example, the diagnosis of a mental health condition can lead to treatments that provide relief. But it may also be the basis for stigmatisation, confinement and unwanted interventions, such as electroconvulsive therapy.[43]

The medical model is not just about the health professions. Disability theorists say it reflects the dominant assumption in Western societies that disability is a tragedy and that people with disability are abnormal and broken.[44] This understanding of disability can negatively affect the way people with disability are treated in all areas of life.[45] It focuses disability policy on the individual rather than on the responses of society to people with disability.[46] As with the charity model, the medical model can generate paternalism and pity and can create social environments that are conducive to discrimination, exclusion, violence, and neglect.[47]

Some theorists argue that while the medical model has greatly influenced the approach of the medical profession and the health system towards people with disability, it is wrong to assume that doctors and other health professionals necessarily make the assumptions incorporated in the medical model. A doctor who offers treatment for the purpose of alleviating the functional limitations associated with a particular impairment may readily accept the injustice of social and economic disadvantages experienced by people with disability.[48]

The social model

The social model, in contrast to the medical model, shifts the focus from a person's impairment to the social environment in which that person lives.[49] Proponents of the social model say that disability arises because society is not structured to include people with impairments.[50] The model rejects the idea that impairment is a tragedy, and instead emphasises social justice and empowerment.[51]

The social model shows how people can be disabled by social barriers, which can include negative or discriminatory attitudes, inaccessible physical environments and inappropriate or inaccessible forms of communication.[52] Some people with impairments may also be disabled by discriminatory systems and structures, such as when they are denied adjustments at school or in the workplace, cannot access public transport, or are denied their right to vote.[53] The aim of the social model of disability is to reshape society so that people with disability are included, empowered and able to flourish in their own way.[54]

The social model distinguishes between individual impairment and disability.[55] It says that disability is the consequence of social exclusion imposed on top of impairment.[56] Critics of the model argue that this distinction diminishes the significance of impairment. They say that impairment is not always neutral and that prevention of impairment, medical cure and disability rights can go together.[57] Social model advocates respond to these critics by arguing that emphasising the social cause of disability has been central to the success of the disability rights movement.[58]

Even critics of the social model accept that it has been enormously influential in bringing about legislative reforms and international agreements such as the *CRPD*, as well as changing community attitudes towards people with disability.[59] The critics also generally accept that the social model correctly identifies that people with disability experience disadvantages because of social attitudes and failures to remove the barriers to their full participation in society.[60] Some critics, however, argue that it is not possible to ignore the effects of impairment – particularly severe impairment – on the experience of people with disability.[61] On this approach, people with disability experience disadvantage because of the interaction of social attitudes and their physical or cognitive impairments.[62] For these theorists, disability is seen as a complex relationship between factors intrinsic to the person, and extrinsic factors such as the social environment and failures of public policy.[63]

Cultural theory

Building on the social model, cultural disability theory highlights the extent to which injustice against people with disability is created and sustained by attitudes and values.[64] Cultural theorists analyse and critique cultural values that can cause discrimination and disadvantage.[65] Cultural disability theory has its origins in the politics of feminist, racial and sexual rights movements.[66] It regards disability positively as an identity of power and pride.[67]

Ableism refers to a set of beliefs and practices about 'typical' or 'normal' abilities and feeds discriminatory attitudes and the refusal to adapt to the needs of people judged as inferior or 'abnormal'.[68] Theorists argue it is a made-up standard or ideal against which a person with disability is perceived as a lesser human.[69] The complementary term, disablism, parallels sexism and racism and focuses on the disablement and disadvantage people experience when society is not structured to include people with disability.[70]

Cultural disability theorists reject the tendency of the social model to focus on social barriers and exclude bodily impairment from the analysis of disability.[71] They argue that while all people with disability experience social exclusion, a person's unique body (including the brain) interacts with the social environment to shape the experience of disability.[72] The interaction between the body and social environment is called embodiment.[73]

Theorists argue that embodied disability gives people a unique perspective.[74] They suggest that people with disability experience and see the social world differently from those with power and privilege (as do First Nations people and other marginalised groups).[75] This embodied knowledge is another reason that theorists say the leadership of, and collaboration with, people with disability is vital in efforts to address disadvantage.[76]

Social role valorisation

Social role valorisation (originally known as normalisation theory) accepts that people with intellectual disability have occupied devalued roles in society, living in segregated institutions and facilities, rendered powerless and subjected to systemic violence.[77] Social role valorisation asserts that people with intellectual disability should be supported to live as close to 'normal' lives as possible.[78] This involves enhancing their image and social situation, moving them from segregated settings to being included in the community, and developing and supporting their personal competencies.[79] Social role valorisation has pushed for social inclusion of people with intellectual disability in schools, the workplace and other community settings.[80]

Capability approach

Some disability theorists have drawn on broader theories of justice in the context of disability. One prominent example is the capability approach, which focuses on what people are capable of becoming or doing.[81] It identifies a list of central human capabilities implicit to a life of worth and dignity, which make it possible for a person to flourish in their own way and provide a minimum basis for human rights. For disability advocates who invoke this approach, the capabilities are an affirmation of a person's effective powers. Their emphasis on universal dignity, capacity, equality, education, autonomy, control and choice is aligned with the empowerment intended by social and cultural theorists.[82]

Critics have expressed concern that the capability approach may diminish the personhood of those whose impairment prevents them from exercising all of the capacities.[83] However, while impairment may prevent some individuals from achieving all capabilities on their own, advocates assert that necessary and appropriate supports should be directed at helping individuals attain those capabilities.[84]

Complementary perspectives and their importance for our work

We understand that the different models and theories of disability provide distinct and complementary perspectives.[85]

The growing consensus that disability is a complex, dynamic interaction between the functioning of people's bodies and the physical and social environments in which they live is apparent in the description of disability in the Preamble of the *CRPD* as:

> an evolving concept and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others.[86]

Models and theories of disability are not just academic issues, but are used by people with disability and advocates to help understand their own experiences and interactions, and inform their proposals for change.[87] Similarly, understanding models and theories of disability informs our work:

- The charity model of disability helps us identify systems that create dependency and make people vulnerable to systemic violence and neglect. It reminds us of the risk of paternalism. It challenges us to value the expertise of people with disability, and work with them to produce effective recommendations. To critique the charity model is not to reject welfare, but to recognise that disability services should support individual autonomy and empowerment.
- The medical model of disability reminds us disability is not a tragedy that needs to be cured, eliminated or segregated. Critiquing the medical model is not to oppose medicine or treatment but to ensure that people with disability have the same rights as those without disability, free of discrimination. It also reminds us of the danger of reducing people to their medical diagnosis or classification.
- The social model of disability ensures that we focus our recommendations on the transformation of social systems that exclude, disempower and discriminate against people with disability. It reminds us that access to the social world is key to reducing violence against, and abuse, neglect and exploitation of, people with disability.

- Cultural theory helps us appreciate that negative values and attitudes can contribute to discrimination against and disadvantage of people with disability. It shows us how ableism frames the discrimination and exclusion experienced by people with disability. It reminds us of the embodied perspective of people with disability and elevates the importance of their leadership and collaboration in making viable recommendations for lasting change.
- Social role valorisation reminds us that people with intellectual disability can be supported to live with the same opportunities available to people without disability. It invites us to make recommendations that reduce the danger of violent institutional control, and encourage and enable social inclusion.
- The capability approach provides us with an ethical foundation for formal human rights mechanisms such as the *CRPD*, and reminds us of the dignity and worth of all people.

Maeve*

Maeve has two master's degrees and understands how the medical system in Australia works. She describes herself as 'a wheelchair user with progressive, untreatable, incurable neurological disease, a brain lesion and severe anxiety and depression with complex trauma, severe migraines with seizure activity'.

In her submission, Maeve told us she experienced continued resistance and neglect over the past two years as she repeatedly sought consultation with neurologists and radiologists at public hospitals and private clinics to discover what her ailments were:

> I saw GPs, and specialist after specialist. I did test after test and no one could find anything wrong ... so I was labelled as 'anxious' and [told] that maybe I just had a low pain threshold.

She said, after another seizure last year, a medical scan finally located a lesion on her brain:

> No one directed me to any disability supports, home help, NDIS, Centrelink. Nothing. Total disposal from the medical system. They wiped their hands of me. So being dismissed makes me worthless.

Maeve told us her increasing disability also revealed access issues at her daughter's school, which did not have lifts or ramps for wheelchairs. Because her daughter's class was on the top floor, she was unable to visit the classroom like other parents. She described how she contacted the school, education authorities and politicians to request that the school provide wheelchair access:

> Two days later I was contacted by the primary school to let me know that my daughter's class had been swapped and was now on the ground floor. I thanked the principal but also planned to continue with my discrimination complaint.

She had been ready to celebrate a win but instead:

> I was victimised, harassed and abused online by a group of other parents who were unhappy about the two classrooms having to swap and had voiced opinions about it being a selfish need for me to have access to my daughter's classroom.

Maeve told us that her attempts to address disability access at her daughter's school proved intimidating, frustrating and fruitless. She noted:

> Buildings should be accessible to all citizens who are eligible to access those buildings; every day, regardless of physical disability or level of fatigue on a particular day. The issue here lies with the buildings, and not with my impairment at all.

*** Name changed and some details removed to protect people's identities. Narrative based on a submission to the Royal Commission.**

Intersectionality: Multi-layered experiences of discrimination

We have pointed out that our terms of reference identify that a person's specific experiences of violence, abuse, neglect and exploitation are multi-layered.[88] Those experiences can be influenced by oppression associated not only with their disability but also their age, sex, gender, gender identity, sexual orientation, intersex status, ethnic origin or race. Our terms of reference direct us to have regard to the particular situation of Aboriginal and Torres Strait Islander people with disability and culturally and linguistically diverse people with disability.

The intersection of ableism with other forms of oppression – such as racism, sexism, ageism or homophobia – works to disempower many people with disability and can have 'serious and sometimes deadly implications'.[89] This idea is known as intersectionality.[90] Professor Kimberlé Crenshaw, an American legal academic who first wrote about the concept of intersectionality in 1989, argued that legal anti-discrimination frameworks operate on the basis of a 'single axis' of discrimination.[91] The consequence of the single axis approach, Professor Crenshaw argued, is that United States anti-discrimination law tends to work for 'those who are privileged *but for* their racial or sexual characteristics'.[92]

The challenges arising for people experiencing intersectional discrimination in Australia are exemplified by the process for making complaints under anti-discrimination law. Federal anti-discrimination laws are contained in a number of pieces of legislation that deal with discrimination on the basis of particular attributes, including the *Race Discrimination Act 1975* (Cth), *Sex Discrimination Act 1984* (Cth), *Disability Discrimination Act 1992* (Cth) and *Age Discrimination Act 2004* (Cth). Generally at a state and territory level, consolidated anti-discrimination legislation tends to include many attributes on the basis of which a complaint may be made.[93] In 2016, the Australian Human Rights Commission's *Willing to work* report highlighted that under Australian federal anti-discrimination laws, 'complainants who pursue action in court must prove discrimination in relation to each attribute (age, race, sex or disability) separately' and that 'this can create difficulties for individuals who have experienced intersectional discrimination; being discriminated against on the basis of a combination of attributes'.[94]

Like disability theory, intersectionality is a tool with which to understand and challenge imbalances of power and privilege in our society.[95] Disability theorists point to the 'overwhelming connection between race, gender, disability, class and other factors in creating and reproducing inequalities', particularly within education, health, economic participation and relationships.[96]

An intersectional approach responds to the fundamental human rights principles of non-discrimination and equality.[97] The United Nations Committee on the

Rights of Persons with Disabilities (CRPD Committee) notes that 'equality and non-discrimination are at the heart' of the *CRPD*, with Article 5 enshrining the principle for people with disability.[98]

Writing about Australia's level of compliance with Article 5 as part of our research program, Emeritus Professor Ron McCallum describes how 'concepts of intersectional discrimination and multiple forms of discrimination are intertwined with one another, however, their differences are significant and are often misunderstood'.[99] Professor McCallum goes on to say that while both approaches 'seek to prohibit discriminatory acts on more than one ground', they 'do so in different ways'.[100] Commentary from the CRPD Committee explains how the concepts differ. It describes multiple discrimination as:[101]

> a situation where a person can experience discrimination on two or several grounds, in the sense that discrimination is compounded or aggravated

and intersectional discrimination as:

> a situation where several grounds operate and interact with each other at the same time in such a way that they are inseparable and thereby expose relevant individuals to unique types of disadvantage and discrimination.

Professor Kimberlé Crenshaw uses the analogy of a traffic accident to distinguish between the two:

> Discrimination, like traffic through an intersection, may flow in one direction, and it may flow in another. If an accident happens in an intersection, it can be caused by cars traveling from any number of directions and, sometimes, from all of them.[102]

It is the 'collision' of discrimination and disadvantage along different axes that creates the unique experiences of many people with disability.

Intersectionality helps explain the multi-layered discrimination experienced by First Nations people with disability and culturally and linguistically diverse people with disability. Dr Scott Avery argues that for many First Nations people with disability, ableism intersects with racism to create a 'heightened vulnerability not adequately explained by racism or ableism alone'.[103] He gives the example of 'an Aboriginal man with cognitive impairment who is harassed at a shopping centre by security guards who assume he is drunk. The physical presentation of a person with cognitive impairment interacts with populist prejudices about Aboriginal people and drinking', resulting in discrimination when he attempts to go shopping or perform other regular tasks in public.[104] Commenting on the hierarchies of disadvantage experienced in Australia, Aboriginal disability rights advocate and founder of the First Peoples Disability Network, Uncle Lester Bostock, described First Nations people with disability as being 'at the lowest rung on the service ladder'.[105]

The report of the Australian Parliament's Senate Community Affairs References

Committee into the violence, abuse and neglect against people with disability describes what has been referred to as the 'multiple disadvantages' experienced by people from culturally and linguistically diverse backgrounds, and 'in particular newly arrived migrants such as refugees and special humanitarian entrants'.[106] However, there is very little dedicated literature or research examining the experiences of violence, abuse, neglect and exploitation of culturally and linguistically diverse people with disability. As such, there is a knowledge gap regarding the intersectional discrimination experienced by culturally and linguistically diverse people with disability.

Intersectionality also helps us to understand the experiences of women with disability, where ableism may intersect with sexism. According to research commissioned by the Royal Commission, women with disability are twice as likely as women without disability to have experienced sexual violence in a 12-month period.[107] Research also shows that women with disability are more likely to be disadvantaged by negative attitudes than men with disability, particularly in the workforce.[108]

Intersectionality recognises the multi-faceted forms of discrimination and disadvantage that people with disability can experience. It helps us understand violence, abuse, neglect and exploitation related to disability in the context of experiences related to other aspects of identity. Applying this approach helps the Royal Commission make these experiences visible and address them through recommendations for change.

Life course approach

The Royal Commission will examine violence against, and abuse, neglect and exploitation of, people with disability through a life course approach. This approach looks at how all stages of a person's life are intricately connected to:[109]

- each other
- other people in society
- the lives of past and future generations.

A life course approach helps us look at each person's life in its entirety in Australian society, rather than thinking about their experiences in the context of systems or services. It helps us to see patterns where particular changes or events predict poor outcomes later in life, and then to make recommendations for reform to disrupt those patterns.[110] It also helps us think about how different groups within each generation face barriers or are given opportunities.

People interact with various systems and services during different stages of their lives that can open or close doors for them, including the education, health care and justice systems. Relationships, economic participation, community participation and homes and living arrangements also play important roles during a person's life. Environments, attitudes, institutions, policies and practices can create barriers to the full participation of people with disability, but they can also facilitate inclusion, belonging and meaningful opportunities to develop in areas of aspiration and potential, particularly if these are provided within human rights principles.[111]

A life course approach offers an understanding of how events in one life stage can have profound consequences across a person's life. For example, traumatic events, such as violent or abusive experiences during a person's childhood, can have significant impacts throughout their life, such as on their mental health, physical health, interpersonal relationships, education, employment and economic security.[112] Research commissioned by the Royal Commission indicates that young people with disability are twice as likely to experience violence in a 12-month period as young people without disability.[113]

Dr Scott Avery has identified how a First Nations child with an undiagnosed impairment or condition who does not have access to appropriate support may have their behaviour misunderstood as delinquent and disruptive. This may result in suspension and exclusion from school, which can have lifelong consequences on employment and increased likelihood of police contact.[114]

Developmental life stages include perinatal (before and after birth), early childhood, school years, adolescence, adulthood, and older age. Disability can disrupt 'normal' expectations about how and when a person transitions through their life course. A life course approach pays particular attention to how people experience transitions between life stages.[115] Transitions may be times of heightened risk for people with disability, particularly without appropriate planning and support.

Conclusion

The four theoretical approaches – human rights, disability theory, intersectionality and life course – are drawn from our terms of reference and inform the work of the Royal Commission. We seek to build on knowledge acquired through decades of research and scholarship to develop an approach to our work that helps us make recommendations for lasting change.

This chapter provides an overview of our understanding of each of these four approaches, and how we intend to use them in our work. Our human rights approach is guided by human rights instruments, with particular attention paid to the *CRPD*. Our understanding of disability draws on the various models and theories developed by academic theorists and disability advocates. Our approach to understanding the multi-layered experiences of people with disability is informed by the work of legal academics, social scientists and advocates who use intersectionality theory. The life course approach helps us understand the context of larger social changes and trends that affect people's individual life pathways. These approaches have been applied to the analysis in Part D, 'Emerging themes and our future direction'.

Endnotes

1 *Letters Patent* (Cth), 4 April 2019 amended 13 September 2019.

2 *Convention on the Rights of Persons with Disabilities*, opened for signature 30 March 2007, 999 UNTS 3 (entered into force 3 May 2008).

3 See, for example, Beth Goldblatt, 'Intersectionality in international anti-discrimination law: addressing poverty in its complexity' (2017) Vol 21(1), *Australian Journal of Human Rights*, pp 48–49.

4 *Letters Patent* (Cth), 4 April 2019 amended 13 September 2019 (g).

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6 *The Human Rights Act 2004* (ACT); *The Charter of Human Rights and Responsibilities Act 2006* (Vic); *Human Rights Act 2019* (Qld).

7 *Convention on the Rights of Persons with Disabilities* Declaration 2009 (Cth), sch 2.

8 *Convention on the Rights of Persons with Disabilities*, opened for signature 30 March 2007, 999 UNTS 3 (entered into force 3 May 2008), art 4.1.

9 *Convention on the Rights of Persons with Disabilities*, opened for signature 30 March 2007, 999 UNTS 3 (entered into force 3 May 2008), arts 3 (a), (e).

10 *Vienna Convention on the Law of Treaties*, opened for signature 23 May 1969, 1155 UNTS 331 (entered into force 27 January 1980).

11 *Letters Patent* (Cth), 4 April 2019 amended 13 September 2019 (e).

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Robbie*

Robbie is 10. He's lonely, distressed and isolated. 'My son is not allowed on excursions, school camps, school awards, and was not included in the school yearbook,' Robbie's mum told us.

Robbie is autistic. He goes to a large mainstream public primary school, where he's the only 'non-mainstream' student.

At school, Robbie is separated from other students by a wooden cubicle partition in the corner of an activity area used by students from other classes. 'The children and parents call him "the boy in the box",' his mum said.

A couple of years ago, Robbie was suspended several times and then excluded from his school for a term. He hasn't been in a classroom with other children since. Now, in the reduced hours he attends school, he has a one-on-one teacher and is in 'the box'.

Robbie is very unhappy about his school experience and is refusing to attend. His mum said Robbie hates not being in a classroom with other children. He feels they've forgotten him and moved on. They have nothing in common with him, as they are all in classes and he isn't. He feels a terrible separation as the only 'non-mainstream' child at the entire school and is very distressed to be known as 'the boy in the box'.

Robbie's mum told us:

> Schools are needed for children such as my son. Deemed too high needs for 'mainstream', yet he is the lone 'non-mainstream' child in his entire school, and not eligible for any other schooling. IQ over 70 means he is prohibited from attending a special unit.

In country areas 'these children end up in the scrap heap with no education … even the basics'.

She would like to see a school in every region to cater for every 'non-mainstream' child with an IQ over 70, 'so they can attend full time like mainstream children are allowed to, and be supported and in classrooms with other children':

> To not be segregated apart from other children in schools. To be included in activities. To not be excluded. To receive support from school staff in relation to their disability and gain an education just like mainstream children have. To be allowed on school camp, excursions, awards, and the school yearbook.

*** Name changed and some details removed to protect people's identities. Narrative based on a submission to the Royal Commission.**

17. Emerging themes and key issues

Key points

- People with disability have told us about their experiences of violence, abuse, neglect and exploitation across a range of settings and contexts. These include systems and services such as education, homes and living arrangements, health, the justice system and the National Disability Insurance Scheme.
- We have also heard about the experiences of people with disability in the context of their relationships, their participation in the community and the economy, and during the COVID-19 pandemic.
- A number of themes are emerging through our work related to the choice and control people with disability are able to exercise across all aspects of their lives, attitudes towards disability, segregation and exclusion, and the use of restrictive practices.
- We have also heard about the access people with disability have to services and supports, and both the positive and negative roles that families, supporters and the workforce can play in the lives of people with disability.
- People with disability have told us about the challenges they face when trying to report violence, abuse, neglect and exploitation, and that their complaints are often minimised, ignored or unreported.
- The lack of data on the violence, abuse, neglect and exploitation experienced by people with disability across all settings and contexts hinders the development of evidence-based policy and practice.
- Existing funding models and structures can create barriers for people seeking to access services and systems, resulting in people with disability not getting the supports they need.

Introduction

As we have noted, the Royal Commission's terms of reference require us to inquire into the 'violence, abuse, neglect and exploitation experienced by people with disability in all settings and contexts'.[1] In our work to date, we have heard about the experiences of people with disability in many systems and services including education, homes and living arrangements, health, the justice system, and the National Disability Insurance Scheme (NDIS).

Like everyone, people with disability live complex and multi-faceted lives that go beyond their interaction with systems and services. We have heard about experiences of people with disability in the context of their relationships and their participation in the community and the economy, including in finding employment and at work. We have also heard how the COVID-19 pandemic and government responses to the crisis affected people with disability.

This chapter provides a synthesis of the emerging themes and key issues the Royal Commission has heard to date. While we recognise that people's lives are affected and shaped by different laws, policies and programs in place across Australia, this chapter does not examine them in detail. We anticipate that an examination will form part of the Royal Commission's future work.

We have explained in Chapter 16, 'Our theoretical approaches' that our work is guided by four approaches, in response to our terms of reference.[2] They are:

- human rights, particularly those set out in the United Nations *Convention on the Rights of Persons with Disabilities* (*CRPD*)[3]
- disability theory, to understand the changing concept of disability over time and disability discrimination
- intersectionality, to understand the 'multi-layered' experiences of people with disability
- a life course approach, to identify patterns across people's lives and trends across generations that may result in worse outcomes for people with disability.

Our terms of reference direct us to have regard to the particular situation of First Nations people with disability and culturally and linguistically diverse people with disability.[4] Chapter 18, 'First Nations people with disability' describes our work so far on that topic.

We are in the early stages of our work with people with disability from culturally and linguistically diverse communities. 'Cultural and linguistic diversity' is difficult to define.[5] In Australia, it tends to describe the community for whom English is not the main language and/or cultural norms differ from the wider community.[6] The breadth of this description makes it hard to measure how many people with disability identify as culturally and linguistically diverse.

Using the indicators recommended by the Australian Bureau of Statistics, in 2018 around 3 per cent of people with disability were born in a country where English was not the main language, who spoke a language other than English at home, and who did not speak English well or at all.[7] For people with disability who do not speak English as their main language at home, the most commonly spoken languages are Arabic, Greek, Italian, Mandarin, Cantonese and Vietnamese.[8] New and emerging communities include migrants and refugees who have recently arrived in Australia, some of whom may be people with disability.[9] Understanding their experiences will be an ongoing focus of our public hearings, engagement, research and policy work. Our approach to engaging with these communities is detailed in Chapter 9, 'Community engagement'. What we have learned from available data is discussed in Chapter 15, 'The nature and extent of violence against, and abuse, neglect and exploitation of, people with disability'.

This chapter draws on the information we have received through submissions, community engagement (including community forums), and responses to issues papers. The Royal Commission has not yet held public hearings to examine all of the themes and issues set out below. While some of the information we have received does not form part of the evidence before the Royal Commission, our work is informed by material from these sources as well as research we have conducted or commissioned and academic literature. We have gathered evidence through our first three public hearings, which are discussed in Chapters 12, 13 and 14. Detailed reports of each public hearing are available on our website. More information on our sources of information is in Part B, 'How we do our work' and Appendix C.

Emerging themes

The Royal Commission has heard about a number of themes that cut across many or all areas of a person's life and the systems they use and rely on. These themes include:

- choice and control
- attitudes towards disability
- segregation and exclusion
- restrictive practices
- access to services and supports
- advocacy and representation
- oversight and complaints
- data
- funding.

Through the course of our inquiry, we will examine how these themes affect the lives of people with disability and the violence, abuse, neglect and exploitation they experience.

Choice and control

> I hope that this Royal Commission can help people with a disability to have choice and control .... People with disability should have a choice ... they should feel free.[10]

People with disability, like everyone, have the right to have control over their own lives, to make their own decisions and to exercise choice. This is sometimes known as autonomy or self-determination. The first general principle of the *CRPD* is 'respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons'.[11]

People have described to the Royal Commission how their ability to make choices can be limited in large and small ways across their lives, including in relation to housing, relationships, health care, work, justice, education, finances and participation in the community.

We have been told about:

- health care decisions made without involvement or consent of a patient with disability[12]
- people with disability being given little or no choice as to where or with whom they live[13]
- people in group homes being unable to choose their own support service provider[14]
- support workers and others 'blocking' intimate relationships between people with disability and the lack of freedom people with disability have to pursue sexual relationships[15]
- gatekeeping by schools curtailing choice for students with disability[16]
- a loss of control in decisions about property or finances[17]
- difficulties associated with developing plans under the NDIS[18]
- a lack of appropriate support available for people with disability within the justice system.[19]

Exercising choice and control and being independent is sometimes confused with being entirely self-reliant and needing no external support.[20] Yet every person, with or without disability, depends on the support of other people and broader social networks. The United Nations Special Rapporteur on the rights of persons with disabilities has said:

> everyone needs support from others at some stage, if not throughout their life, to participate in society and live with dignity. Being a recipient of support and offering support to others are roles we all share as part of our human experience, regardless of impairment, age or social status.[21]

The provision of appropriate support can enable people with disability to maximise their autonomy.[22] Autonomy implies that people are entitled to choose the support that meets their individual needs.

Support with decision-making may be particularly useful in optimising choice and control for people with disability, including people with cognitive disability.[23] The Committee on the Rights of Persons with Disabilities (CRPD Committee) has described a range of formal and informal arrangements that can support decision-making, including exercising legal capacity.[24] These are reflected in the various measures people have told us about that can aid their decision-making, including:

- guided choices with appropriate supports to build decision-making skills[25]
- advocacy, including self-advocacy, advocacy on behalf of others, and systemic advocacy[26]
- peer support, peer education or awareness raising.[27]

Numerous reviews and inquiries have examined choice, control and decision-making for people with disability in Australia.[28] Several have recommended an increased focus on supported decision-making.[29] For example, the National Decision-Making Principles outlined by the Australian Law Reform Commission in its 2014 report, *Equality, capacity and disability in Commonwealth laws* and related *Will, preference and rights guidelines,* promote supported decision-making as a way for people with disability to exercise their right to make choices for themselves.[30] Guardianship and administration processes and orders are discussed further in the section on ‘Justice’ later in this chapter.

As the work of the Royal Commission continues, we will examine the links between limits on choice and control and the violence, abuse, neglect and exploitation experienced by people with disability.

Attitudes towards disability

> Ableism is the foundation of our oppression and consequent suffering … The deadly bigotry of low expectations and the consequences over a lifetime are killers.[31]

Attitudes can contribute to violence against, and abuse, neglect and exploitation of, people with disability. People with disability, their family members and supporters have told us about the negative or harmful attitudes they often face, as well as assumptions other people make about their quality of life and value to society. They have described how these attitudes can affect or influence their experiences across many areas of life.

Attitudes are thoughts, beliefs and feelings that can influence behaviour.[32] While academic research reveals varying opinions about the influence of attitudes, it is widely accepted that attitudes can either directly or indirectly affect behaviour.[33] Attitudes can be explicit and held knowingly, or implicit and exist subconsciously.[34] Subconscious attitudes are often based on hidden, negative thoughts and feelings known as unconscious bias. This form of bias is very common and research suggests that it can influence behaviour.[35]

Attitudes are complicated to measure, and it is difficult to establish a causal link between attitudes and behaviour.[36] While attitudes towards people with disability may have improved over time, subtle forms of prejudice and harmful behaviours against people with disability still persist.[37] British disability academic Professor David Bolt argues that 'attitudes and actions – not to mention words – are intrinsically connected'.[38]

Attitudes can manifest as negative assumptions, low expectations and discrimination. People with disability and their family members have reflected on their experiences with harmful attitudes held by the wider community, including de-valuing, stereotyping and a lack of understanding and acceptance. One person with disability told us:

> I have been abused because I am different, labelled 'disabled' and misunderstood. I don't want to be scared any more due to other people's inability to accept someone that is different.[39]

Another person described how their perception of attitudes towards disability affected their sense of self:

> I was not identifying as a person with a disability … What underpinned this reluctant to identify as a person with a disability was a fear; I feared I would certainly be discriminated against, or stereotyped.[40]

Negative attitudes towards disability can intersect with attitudes towards age, sex, gender identity, sexual orientation, and race, ethnicity or First Nations identity. Data from the Australian Bureau of Statistics indicates that First Nations people with disability are almost twice as likely to experience discrimination as non-Indigenous people with disability.[41] First Nations disability expert Dr Scott Avery discussed the 'double disadvantage' experienced by First Nations people with disability at Public hearing 4: Health care and services for people with cognitive disability. He said:

> You need to see it in terms of a power and where people sit in the social hierarchies of power … It's this notion of being double-disadvantaged. So, you can experience racism, you can experience ableism, but there are some times when those two come together.[42]

The Royal Commission is at an early stage in its inquiry into the link between attitudes towards disability and the violence, abuse, neglect and exploitation experienced by people with disability. Initial insights into attitudes towards disability and the attitudinal barriers faced by people with disability indicate it will be important to our ongoing work.

Kora*

Kora's family always expected her to be a doctor. From a young age she knew there was never another option.

In her submission, Kora told us she excelled in high school and it was no surprise when she was accepted to do medicine at a prestigious university.

At the beginning of her first year Kora disclosed to the university she had a mental illness that affected her study. Her doctor had told her she had 'obsessive compulsive disorder and depression'. He had also said, 'these conditions do exacerbate at times of stress and interfere with concentration, focus and energy'.

According to her submission, the director of student services told Kora she 'would either have to "bite the bullet" and go through with the course, "graduate with a Bachelor of Medical Science" or fail out'. The school of medicine would make 'no time adjustments during the semester or prolong the degree'.

Feeling there was no other option, Kora decided to continue with her studies. She found the culture very non-accepting of people who were different, and there were instances of bullying and harassment in tutorial groups.

In the first semester of her second year, her illness was acute and she failed two out of four subjects. Kora explored possibilities with the school of medicine to reduce her workload and continue the year part time, but she was told there was no flexibility in the program and subjects couldn't be completed out of order.

She found this baffling because she wasn't proposing to complete subjects out of order. She was forced to sit out the year and redo the subjects the following year.

Kora said she repeated the second year and prepared thoroughly for her end-of-year clinical exams:

> I made sure I knew everything for my OSCEs [Objective Structured Clinical Exams] – then on the final assessment my anxiety resurfaced, I ran out of time in all but 2 stations and I fell to pieces.

The supplementary exams were scheduled to take place at a time when she was overseas with her family, and she was refused alternative dates.

Kora told us she received material about third-year orientation, but on the first day she was advised 'her name wasn't on the list'. Kora was told her enrolment had been cancelled. The reason given was that the Bachelor of Medicine and Bachelor of Surgery (MBBS) she had been enrolled in had been replaced by the Doctor of Medicine (MD). This meant students now only had two chances to repeat failed courses rather than the three chances they had previously. Kora was out of chances.

Kora felt she had been treated unfairly. Not only was no consideration or support given to her after she disclosed her illness but also she was a victim of changing rules, caught in the cohort of students transitioning from an MBBS to an MD degree.

She complained to the university and the state health ombudsman to no avail. Some clinical tutors and the university counselling and disability staff were supportive, but they had no power to influence decisions.

Kora told us she doesn't understand why some medical schools are able to 'exert their autonomies over the rules of equity of the university to which they are affiliated'.

She would like to see more flexibility in medical training programs so students of different abilities can succeed. Kora said she feels that the 'one size fits all approach' she experienced de-humanises everyone.

Luckily she has found that not all institutions are the same. She is currently studying at a different university, 'which is a much more supportive environment'.

*** Name changed and some details removed to protect people's identities. Narrative based on a submission to the Royal Commission.**

Segregation and exclusion

> Negative perceptions, negative judgements and negative expectations are reinforced and become woven into the fabric of our community when the 'other' places for the 'other' people exist.[43]

Segregation is when people with disability are separated from the rest of the community or from settings where people without disability can access supports and services and participate in community and economic life. Historically in Australia, social policy supported the segregation of people with disability in institutions that provided housing, recreation, employment and education, leaving families of people with disability with few options.[44] Some academics have argued that the prolonged segregation of people with disability from mainstream society has contributed to the broader lack of understanding and negative attitudes towards disability.[45]

Exclusion is driven by unequal power relationships and can occur at an individual, relational, community, societal and economic level.[46] Exclusion occurs when people are denied access to the social, economic, political and cultural systems that enable a person to be part of the community. General comment No. 5 adopted by the CRPD Committee states that social exclusion 'engenders stigma, segregation and discrimination, which can lead to violence, exploitation and abuse in addition to negative stereotypes that feed into a cycle of marginalisation'.[47]

> People started avoiding me, even crossing the street to avoid talking to me. I didn't think I was that bad that I would be deliberately avoided and socially excluded.[48]

A shift towards policies of deinstitutionalisation has meant that many larger institutions are now closed. However, a number of people with disability – particularly people with cognitive disability – remain segregated from the wider community in institutionalised settings.[49] Research into the experiences of children with disability in institutional contexts for the Royal Commission into Institutional Responses to Child Sexual Abuse suggests that: 'Segregation and exclusion in closed institutional contexts away from public scrutiny leaves children (and adults) with disability at heightened risk of violence and harm, including sexual abuse.'[50]

This Royal Commission has heard about the experiences of people with disability of violence, abuse, neglect and exploitation across a range of segregated settings, including education, homes and living, and employment. Submissions and responses to issues papers have described how, even in smaller institutions, people with disability continue to be affected by cultures and practices within organisations that do not value their autonomy or dignity.[51]

Women with Disabilities ACT said that most group homes 'currently function as mini-institutions that isolate residents almost completely from the community outside the home's walls'.[52] We have heard that this can have a negative effect on a person's opportunity to build meaningful relationships with friends and family, which can protect against violence, abuse, neglect and exploitation.[53] Ms Rosemary Kayess, Senior Research Fellow at the University of New South Wales and Vice-Chair of the CRPD Committee, gave evidence at Public hearing 3: The experience of living in a group home for people with disability. She said that:

> By accessing the community, people with disability have the opportunity to build trusting relationships with a variety of people as contrasted to living in a closed environment where they are limited to relationships with service providers and other people in that environment. It is access to the community at large that reduces the risks for exploitation, violence and abuse.[54]

The CRPD Committee describes segregated education as 'separate environments designed or used to respond to a particular or various impairments, in isolation from students without disabilities' and considers the segregation of students on the basis of disability a form of discrimination.[55] At a community forum, Flinders University academic Dr Peter Walker told us, 'Separate provision enables schools to look away. It allows them to think of students as not theirs and of themselves as teachers as not being capable.'[56]

People with disability may also be employed in segregated workplaces. Australian Disability Enterprises (ADEs), sometimes referred to as 'sheltered workshops', largely employ people with disability with higher support needs.[57] We have heard about the lack of quality and usefulness of work in some ADEs, poor workplace conditions and difficulties in transitioning to open or non-segregated employment.[58]

> We keep talking about how different these people are, we laugh at them, we mock them, we continually talk about what they can't do. We put them in low paid, hard factory jobs and we pay them in coins. For the whole of their life they have been put down and kept in sheltered workshops.[59]

ADEs and productivity-based wages are discussed further in 'Economic participation', later in this chapter.

Day programs are activities provided for people with disability. They are usually structured so that only people with disability attend, creating settings that are separated from the wider community. While some submissions have described the benefits of day programs, we have also heard that some people with disability do not have a meaningful say over how they access them.[60] At Public hearing 3, Ms Naomi Anderson, a solicitor and disability advocate, gave evidence of people with disability who have 'no choice, no control' over which activities they join.[61]

First Nations people with disability and culturally and linguistically diverse people with disability may experience intersecting disability discrimination and racism, resulting in exclusion and isolation.[62] For First Nations people with disability, ongoing intergenerational trauma resulting from colonisation and subsequent policies of 'protectionism' and assimilation may contribute to these experiences.[63]

Research by Dr Avery indicates that First Nations people with disability experience constant and acute social exclusion and isolation from the broader Australian community.[64] Drawing on data from the 2014–15 Australian Bureau of Statistics *National Aboriginal and Torres Strait Islander Social Survey*, Dr Avery reported that 'Aboriginal and Torres Strait Islander people with disability experience social isolation at far higher rates than other population groups', which is expressed through acquired mental health conditions.[65] He concludes that the 'structural disempowerment of being "out of sight, out of mind" manoeuvres people into socially isolating situations where they become vulnerable to personal incidents of violence'.[66]

An Australian study into people with disability from refugee backgrounds shows that stigma and discrimination present barriers to social inclusion, which negatively affected their access to services and relationships with families and communities.[67] The study also reports that families from a refugee background that include a person with disability often experience isolation within their country of origin communities.[68]

The Royal Commission will examine the impacts of segregation and exclusion – including whether they lead to increased violence, abuse, neglect and exploitation – throughout the lives of people with disability. This will include transitions from childhood into adulthood and from education into employment.

Danny and Orton*

Danny's father, Orton, made a submission about Danny's experiences at school. Orton told us that Danny is being forced out of his school because he is different. Danny is autistic, has attention deficit hyperactivity disorder and anxiety, and is gifted. He is a pleasant kid who gets on well with his classmates and is 'well-mannered … until provoked'.

Orton told us that Danny suffered badly during his first year of school because no-one understood him. On one occasion, Danny was dragged, screaming and crying, by two teachers, losing his shoes in the process. A teacher's aide also once dragged him across the floor when he was upset.

One day the school principal held Danny down with a booted foot, bruising Danny's body. It happened in the morning and Danny was then isolated from his class for the rest of the day. Not knowing anything was wrong, Danny's mum picked him up at the usual home time, and noticed the bruising.

Another time Danny, in extreme frustration, stripped off his clothes down to his underwear. Orton and Danny's mum went to see the principal and deputy principal, who 'bragged' about how they had laughed at Danny when he did this. Orton couldn't believe it. 'This was a child, not someone for them to laugh at and then think it's clever to tell his parents.'

The school used a traffic light system for managing difficult behaviour. In Danny's first six months at school it became clear that the traffic light system was not working for him and that he reacted violently when he was 'marked down'. At least one teacher asked the principal if she could stop using the system on Danny in order to prevent his violent outbursts.

Despite knowing that the traffic light system could cause Danny to have violent reactions, the principal refused to stop using it on him. Indeed, on two occasions the system was used on Danny in a way that was outside normal procedures. Orton felt it was to deliberately provoke Danny so the principal could build a case to expel him from the school.

'For a Principal or a teacher to instigate a violent reaction from a child and then blame the child for his actions is shameful,' Orton said.

Orton believes that behaviour management strategies like the traffic light system not only fail the children but also represent a form of bullying and humiliation.

*** Names changed and some details removed to protect people's identities. Narrative based on a submission to the Royal Commission.**

Restrictive practices

Restrictive practices are interventions or actions that limit the rights or freedom of movement of a person.[69] In Australia, restrictive practices can be used in certain circumstances to prevent or protect people from harm, including perceived harm.[70] Restrictive practices may be used to prevent an individual from expressing what are characterised as 'behaviours of concern' for the protection of themselves or others.[71]

Restrictive practices include seclusion and the use of restraints. The National Framework for Reducing and Eliminating the Use of Restrictive Practices in the Disability Service Sector defines seclusion as 'the sole confinement of a person with disability in a room or a physical space at any hour of the day or night where voluntary exit is prevented, implied, or not facilitated'.[72] Types of restraints are defined as:[73]

- physical restraint – 'the sustained or prolonged use or action of physical force to prevent, restrict or subdue movement of a person's body or part of their body, for the primary purpose of influencing a person's behaviour'. An example is holding a person down so they cannot move.
- chemical restraint – 'the use of medication or chemical substance for the primary purpose of influencing a person's behaviour or movement'. An example is using medication to sedate a person.
- mechanical restraint – 'the use of a device to prevent, restrict or subdue a person's movement for the primary purpose of influencing a person's behaviour but does not include the use of devices for therapeutic or non-behavioural purposes'. Examples include tying a person to a chair, disconnecting the power of an electric wheelchair or taking away a person's communication device.

Additional restrictive practices regulated in some jurisdictions include:[74]

- psycho-social restraints, which usually involve the use of 'power-control' strategies. An example is telling a person, without reasonable justification, that an everyday activity is too dangerous.
- environmental restraints, which restrict a person's free access to all parts of their environment. An example is locking an area of a group home to prevent people accessing it.
- consequence driven practices, which involve the withdrawal of activities or items.

All states and territories have laws, policies, principles, standards and practices for the use of restrictive practices but there is no uniform framework that regulates them across all jurisdictions and settings in Australia.[75]

The CRPD Committee has urged Australia to create 'a nationally consistent legislative and administrative framework' to protect people with disability from the use of 'psychotropic medication, physical restraint and seclusion under the guise of "behaviour modification"' and to eliminate 'restrictive practices in all settings'.[76]

Psychotropic medication broadly refers to any drug capable of affecting the mind, emotions and behaviour and can include stimulants, antidepressants, antipsychotics and anxiolytic/hypnotics.[77]

Previous inquiries have highlighted concerns about the use of restrictive practices, including improper use and inconsistent regulation.[78] We have received information about the use of restrictive practices in educational, residential, health and detention settings, which is described below.

Submissions from parents of students with disability describe the use of seclusion and physical and chemical restraints in schools.[79] One parent described how a teacher physically held their child down, injuring the child.[80]

We have also heard about the use of restrictive practices in group homes. One submission from an advocate for people with disability described the use of physical restraints:

> DMc was tied up with a bungy cord to keep him seated in a chair tied to the kitchen table so that he was forced to sit at the table for 8 hours or more, only getting up from the table for a bathroom break a couple times a day … for years he remained tied to the kitchen chair.[81]

A number of submissions report that the use of restrictive practices is widespread in group homes.[82]

Restrictive practices are also used in health settings. The Australian Institute of Health and Welfare (AIHW) reports that in 2018–19 people were forcibly isolated 11,944 times in public sector acute mental health hospitals.[83] People were physically restrained by staff or devices 18,690 times and mechanically restrained 991 times during the same period.[84] Research suggests medication is used to restrain people with disability to manage behaviours of concern and that psychotropic medication in particular is used on people with intellectual disability as a matter of routine and in the absence of any therapeutic objective or benefit.[85]

In one submission, a person with disability described his experience of chemical restraints in a paediatric mental health care ward:

> I was forced to take medications not directly tethered to the treatment of my diagnosis but as a tranquilising sedative. In this facility I could be considered violent for raising my voice above a whisper or requesting to see a doctor or other form of oversight.[86]

In response to our *Health care for people with cognitive disability issues paper*, the Queensland Office of the Public Guardian told us that although there has been a reduction in the use of chemical restraints in Queensland, there is still an over-reliance on medications to manage behaviour.[87] The Centre for Developmental Disability Health at Monash Health told us that when individuals with an intellectual and/or developmental disability arrive at hospital they are almost always put on anti-psychotic medication.[88] The Centre explained this is used as a chemical restraint in an attempt to manage their behaviours because 'the environmental, communication and support needs people with cognitive disability require are difficult or impossible to provide within the hospital'.[89]

> There is no real ‘help’ for the mentally ill, only heavy sedation authorised by a ‘psychiatrist’.[90]

We have also heard about the use of seclusion in detention settings as a restrictive practice. In one submission, the parents of a young man in prison described how the prison did not provide for their son’s mental health needs. When their son tried to indicate he was ‘not doing well mentally and asked to see someone’, it was interpreted as him having suicidal thoughts and his parents said he was placed in confinement for four days.[91]

The Royal Commission will examine the use of restrictive practices on people with disability, whether it is a disability-specific form of violence and its links to other forms of violence, abuse, neglect and exploitation. We will consider its impacts on a person with disability, including serious physical injury, psychological harm and even death. We will also consider how the use of restrictive practices can be avoided, prevented or minimised, and if there are circumstances where they are required, what rules and safeguards should apply.

Access to services and supports

The Royal Commission has heard about the barriers that people with disability can face when attempting to access services and supports. Services and supports range from everyday essentials, such as supermarkets, public transport, education and health care, to those that are disability-specific. In the section below, we outline what we have heard about how people who provide or facilitate access to these services and supports can be a source of safety, helping prevent and protect people with disability from experiencing violence, abuse, neglect and exploitation. This includes family members, friends, volunteers and support workers. We have also heard how those people can minimise or ignore violence, abuse, neglect and exploitation when it occurs, or be the source of harm themselves.

The role of families and supporters

Our terms of reference identify that families, carers, supporters and advocates can play a critical role in providing care and support to people with disability.[92]

We have heard about the need for supportive networks, including family, friends and communities, in the lives of people with disability. One family member told us, ‘the most important resource available to people with disability is their family and network of close friends and supporters’.[93] At Public hearing 3, Mr Kevin Stone AM, CEO of Victorian Advocacy League for Individuals with Disability (VALID), said families can be important advocates for people with disability and when equipped with the right skills, they can be a ‘phenomenal force’.[94]

However, we have also heard about violence against, and neglect, abuse and exploitation of, people with disability by family members, including intimate partners, spouses and siblings, as well as extended family, kinship members, friends and other people who should have been providing support. These experiences of domestic, family and sexual violence are discussed further in the section on 'Relationships' later in this chapter.

Workforce skills and management

People with disability have described experiences of violence, abuse, neglect and exploitation from support workers, including sexual assault.[95] We have also heard how support workers have failed to provide appropriate or adequate support and assistance. For example, one submission described a support worker saying to the mother of a child with disability that, 'if things got really desperate we should just "abandon [our child] in respite". Drop him off and never come back.' [96]

We have heard about the need to improve workforce capability, support, oversight and management to reduce violence, abuse, neglect and exploitation and improve responses across:

- supported accommodation and other support services[97]
- education settings[98]
- health services[99]
- the criminal justice system[100]
- domestic and family violence services[101]
- specialist disability services such as ADEs and day programs.

We have also heard about health professionals not having adequate training to meet the health needs of people with disability. Witnesses at Public hearing 4 suggested that some health professionals do not have the knowledge, skills and training to provide quality health care to people with disability. This is also discussed in Chapter 14, 'Public hearing 4: Health care and services for people with cognitive disability'. Ms Kim Creevey, the mother of a child with disability, told the Royal Commission that:

> There needs to be a concerted effort to provide substantial training and education for all medical staff about unconscious bias and the impact it might have on their decision making about treating a person with disability.[102]

The Centre for Developmental Disability Health also told us about the need for further training for disability support workers, as they can play a key role in monitoring health and facilitating people's access to health care.[103]

However, witnesses at Public hearing 3 suggested qualifications alone are not enough. Dr George Taleporos of the Summer Foundation gave evidence that:

> people need to know how the person needs to be supported. They need to know how to provide support safely, competently in a way that respects the person but I can confidently tell you hand on heart under oath, mandatory qualifications for all support workers is not the answer.[104]

Nina and Frieda*

This experience … has brought us heartbreak beyond belief.

Nina is in her forties, has an intellectual disability, little communication and a range of medical issues.

Nina's mother, Frieda, made a submission about what happened a few years ago when Nina moved into a new home that had been organised by a disability organisation.

The family had spent five years planning and searching and getting Nina ready to go into supported accommodation. 'But it has taken [them] 5 months to destroy our hopes and dreams, for [Nina's] future and ours,' Frieda said.

Frieda told us that the home had a high turnover of inexperienced staff – 20 new staff, in a house with only two residents, in the five months Nina stayed there. During that time, Frieda said, Nina had two falls, bruises on her arms, and lots of big mosquito bites that became infected. The meals were poor, usually frozen food.

Frieda told us Nina was traumatised by the lack of care. She said that staff routinely failed to give Nina her medications on time and would not follow her routine. This would make Nina angry and confused to the point where she started banging her head on the walls.

Meanwhile, Frieda said, she herself felt like an 'unwelcome guest'. The service provider seemed to expect her to dump her child and 'let them deal with it'.

The family removed Nina from the home for good one day when they found her sick with vomiting and diarrhoea, Frieda told us. Over the five months of Nina's stay they had complained to the house manager and the area coordinator but were 'fobbed off'. When they removed her, they wrote to the senior management of the organisation explaining why she wouldn't be returning.

After that they went to the state disability complaints office. Frieda said the office took on the complaint but, as Nina had left the accommodation there was little in the way of resolution. There was no apology.

Frieda told us that Nina is still affected by the trauma of what happened to her in that home. She said:

> My husband and I were also traumatised with this experience. As we are aging, we had hoped that we would find somewhere [Nina] could be cared for and have a good life.

*** Names changed and some details removed to protect people's identities. Narrative based on a submission to the Royal Commission.**

Disability advocate and academic Dr Peter Gibilisco described the importance of a flexible system that allows for tailored support and quality relationships with support workers:

> Having a good team of support workers who have spent time with me every day and come to understand my disability has been highly beneficial. This is especially the case for my academic support workers whom I hire independently outside of the disability service providers. The result of my relationships with my support workers can be seen in my achievements, both academic and personal in recent years, including the publishing of my third book, publishing an article or blog post almost every week and gaining access to the NDIS. The support system that has been created here is one that is tailored to my particular needs and causes no harm because it is not standardised.[105]

We have heard from First Nations organisations that strive for practices that support First Nations people with disability, underpinned by culturally safe workplace procedures and conduct.[106] Such practices are sometimes referred to as 'our way of working' and may include:[107]

- requirements to employ First Nations language speakers
- respecting and prioritising the choice of a person with disability to be on Country
- a requirement to decode medical and disability terminology into First Nations languages
- gender matching for clients and the workforce
- family-based collective decision making.

We heard evidence that some disability support services have a staff-centred approach, which prioritises efficiency over the person with disability. Ms Sam Petersen, a woman with disability who lives in a group home, described having three support workers dressing her to meet a given timeframe:

> They saw it as being efficient but I saw it as taking my say away … one support worker was putting my catheter bag on and then another support worker was putting my bra on and I was indicating 'wait, the bra straps have come loose' and the one putting my catheter bag on would be saying in an angry voice, 'You need to concentrate on me.'[108]

Professor Christine Bigby, Director of the Living with Disability Research Centre at La Trobe University, gave evidence that rosters and activities in group homes are often 'organised around the staff and to support staff needs'.[109] Professor Bigby described how active support that engages the person with disability builds their independence and skill development.[110]

Barriers to accessing services and supports

People with disability can face a range of barriers to accessing services and supports. These include:

- environmental barriers, such as when a physical space is not accessible[111]
- attitudinal barriers, such as discrimination and unconscious bias, seeing the disability rather than the person, and negative assumptions about people with disability, their needs, preferences and aspirations[112]
- communication barriers, which can arise when information is not accessible, such as audio or verbal communication being unavailable in written text, Easy Read, Auslan or captioning for people who are deaf, have hearing impairments or have complex communication needs and do not have appropriate technology and support to communicate[113]
- institutional barriers, such as laws, policies, practices or strategies that discriminate against people with disability, and inaccessible public transport, and buildings and services that are not user friendly.[114]

We have heard about 'gatekeeping practices', where people and organisations put barriers in place to stop people with disability engaging in mainstream services. We have been told about schools refusing to enrol a child with disability, only offering part-time enrolment, encouraging enrolment in special/segregated education settings or encouraging home schooling.[115] Some families and students have said that although the law provides students with disability an equal right to education as people without disability, in reality this is not always the case.[116] Gatekeeping practices are discussed in Chapter 12, 'Public hearing 2: Inclusive education in Queensland – preliminary inquiry'.

People with disability have also told us about barriers to accessing health care, including high costs, long waiting lists, physically inaccessible services and complex medical forms.[117] Research by the AIHW suggests that a lack of timely, available, affordable and physically accessible services can be a barrier to basic health care for people with disability in Australia.[118]

Barriers faced by First Nations people with disability

We have heard about a lack of appropriate services and supports that can particularly affect First Nations people with disability. The MJD Foundation is a charitable foundation that works in partnership with First Nations people living with Machado-Joseph Disease, a hereditary neuro degenerative condition. It noted in its submission that people with disability who live in remote communities often lack access to services and supports, worsened by poor or inaccessible infrastructure.[119] At Public hearing 4, Narelle Reynolds, a First Nations woman, told us one of the reasons she moved her family from their rural community to a coastal town was to access culturally safe health services for her son with disability, who had cancer.[120]

The Royal Commission has not yet held a public hearing to examine issues relating to the NDIS. However, we have received submissions from individuals and organisations suggesting that the structure of the NDIS can limit First Nations people with disability from accessing culturally appropriate care. The Royal Commission has also heard that some First Nations community-controlled organisations feel excluded by the NDIS and consider that their role has been diminished since its introduction:

> People have to deliver NDIS under a tree in the remote areas … [This is] how it has to be done – because you can't bring services out to remote area if they've got no facility to work in it.[121]

First Nations people have also shared their concerns over the inability of the NDIS to support First Nations people with disability who wish to return to Country. They say that the NDIS fails to recognise that maintaining the connection to Country is fundamental to their cultural identity, wellbeing and ability to thrive.[122]

The Australian Bureau of Statistics *National Aboriginal and Torres Strait Islander Health Survey 2018–19* suggests that barriers for First Nations people with disability accessing health care can include:[123]

- the cost of health care (raised by 15 per cent of respondents)
- the waiting time for, or lack of availability of, health care (raised by 12 per cent of respondents)
- feeling embarrassed, afraid of or dislikes the medical officer (raised by 11 per cent of respondents)
- lack of transport or health care was too far away (raised by 7 per cent of respondents).

First Nations people with disability have also told us about the role of racism, and particularly institutionalised racism, as part of their experiences of violence, abuse, neglect and exploitation.[124] The Lowitja Institute and Just Reinvest NSW expressed concern about indirect institutional or systemic biases that First Nations people with disability experience when accessing services, housing and employment, and exercising their rights.[125] Likewise, the Queensland Human Rights Commission emphasised the 'layer of hardship' that racism adds for First Nations people with disability, particularly in relation to their over-representation in the justice system, which in turn may increase their vulnerability to abuse.[126] This is discussed further in Chapter 18, 'First Nations people with disability'.

Barriers faced by culturally and linguistically diverse people with disability

Culturally and linguistically diverse people with disability can also encounter particular barriers to accessing services and supports. The *Disability rights now 2019* report noted the challenge of accessing information can be heightened for people with disability from culturally and linguistically diverse backgrounds when information is only provided in English.[127]

Accessing supports can also be challenging for temporary residents, including asylum seekers and migrants with disability. The *National Disability Insurance Scheme Act 2013* (Cth) requires a prospective NDIS participant to reside in Australia and to be an Australian citizen, permanent visa holder or protected special category visa holder.[128] The *Disability rights now 2019* report identifies that these requirements create difficulties for asylum seekers and people with disability living in Australia on temporary visas from accessing services and supports under the NDIS.[129]

Prospective entrants to Australia are required to meet health criteria under the *Migration Act 1958* (Cth) and *Migration Regulations 1994* (Cth).[130] The criteria require a prospective visa holder to be free of a disease or condition that would be likely to require health care or community services in Australia.[131] Any necessary health care or community services must not result in a significant cost to the Australian community, or prejudice the access of health care or community services of an Australian resident or permanent resident.[132] These provisions may operate to exclude people with disability from being granted a visa to enter or remain in Australia, or to limit their level of access to health care or community services. In 2019, the CRPD Committee raised concerns about 'the health requirement in the Migration Regulations 1994, which allows for discrimination against persons with disabilities in asylum and migration procedures'.[133]

In the course of our inquiry, we will examine the provision and accessibility of services and supports across Australia, and how this impacts on the violence, abuse, neglect and exploitation experienced by people with disability. We will also consider the role families, supporters, carers, advocates, support workers and the workforce may have in contributing to, or reducing the risk of, violence, abuse, neglect and exploitation.

Milo*

Milo has severe to profound hearing loss. He uses hearing aids to listen, but his preferred way to communicate is with Auslan. He is active in the deafblind sector.

In his submission, Milo said that little progress has been made for deaf and deafblind children in educational settings since he was a student.

> We still see deaf, deaf with additional disabilities and deafblind children and adults being denied the right support they need in life to get ahead in life, to even get a good life.

Milo said he experienced and witnessed abuse and discrimination at school. As a student he was profoundly deaf but could speak clearly. The teachers would sometimes single him out as an example to others in the class. 'The teacher would exploit my ability and would say to my peers that they failed.' This embarrassed and traumatised him.

On one occasion Milo tried to explain to the teacher the effect this was having on his friends. 'Of course I was using gesture, pointing and illustrating what I was saying.' This earned Milo a slap across the face. He was forced to hold his hands behind his back and repeat everything, speaking without using his hands.

'In the school system,' Milo said, 'we were clearly denied access to a visual language.' The discrimination and limits on language were isolating, and 'the sheer isolation was a big factor that caused most of us to develop mental health issues, depression and anxiety'. He noted, 'When you limit a person's range of communication abilities and confine it to speech only, you run the risk of increasing the level of violence, abuse, neglect and exploitation.'

There was also a lot of physical and psychological abuse, but it was always covered up 'and we didn't know how to communicate these things'. 'We never had that support during our formative years, we did not even understand we had rights and that we could complain.'

Milo was thinking about becoming a teacher of deaf people and he was aware of a university course that would provide support with note-takers, interpreters and tutors. However, he said that often when deaf people begin to practise teaching 'they are treated badly by teachers and bullied by professionals'. 'It is also really disturbing to see the treatment of deaf children in primary and high school.'

Milo believes the education system continues to marginalise deaf and hard of hearing children by not encouraging sign language usage. Also, it won't encourage deaf adults to have contact with deaf children in integrated settings. If the children had that type of contact, they might see how other deaf people have succeeded in life. ‘No access to live role models increases isolation,’ said Milo.

Milo is also upset about the lack of skilled deafblind specialists available to work with deafblind people or provide training to service providers to deafblind people. Without training, he said, services provided to deafblind people are ‘dumbed down’, increasing their sense of anxiety and lack of self-esteem. Milo told us the problem extends to group homes and day programs, which don’t have the resources to provide appropriate and trained people to work with deafblind people.

Milo told us he thinks there needs to be greater awareness around violence, abuse, neglect and exploitation of deaf, deafblind and deaf people with additional disabilities. He would like to see training, information and support made available to them in their preferred mode of communication.

*** Name changed and some details removed to protect people’s identities. Narrative based on a submission to the Royal Commission.**

Advocacy and representation

> The only strategy I've ever seen capable of making a difference is advocacy and self-advocacy, particularly self-advocacy, empowering people to stick up for themselves.[134]

Advocacy and representation enable people with disability to have their voices heard at all levels of society. Disability advocacy is acting, speaking or writing to promote, protect and defend the rights of people with disability, whether individually, using the law, or by changing legislation and policy.[135] Self-advocacy empowers people with disability to speak up for themselves, often in everyday situations. In Australia, there are disability advocacy and representative organisations, which include Disabled Peoples' Organisations and family advocacy organisations. They have a role in monitoring and implementing the *CRPD.*[136]

We have heard from numerous advocacy and representative organisations. Some submissions and issues paper responses have also proposed that advocacy, including self-advocacy, is a key measure for addressing violence, abuse, neglect and exploitation.[137]

At Public hearing 3, witnesses gave evidence about the importance of advocacy for people with disability in preventing abuse in group home settings.[138] Janine Toomey, Executive Director for Disability and the NDIS at the Department of Health and Human Services in Victoria, described self-advocacy as part of a zero-tolerance approach to abuse.[139] Pauline Williams of Action for More Independence and Dignity in Accommodation (AMIDA) described the Self-Advocacy Resource Unit, where people with disability can learn new skills and form support groups, play a role in civil society and lobby for change.[140] Dr Colleen Pearce described 'peer support, peer education, and advocacy as the fundamental building blocks' for empowering people with disability.[141]

We have also heard that existing advocacy services are under-funded.[142] One response to the *Rights and attitudes issues paper* argued that 'there is little to no advocacy support available that suits [people with] complex and challenging disabilities and their families', and called for more individualised and ongoing advocacy support.[143]

A submission by the Victorian Commission for Children and Young People discussed the need for more independent advocates who can work with children with disability.[144] Others have told us that there should be greater support for, and/or access to, independent advocacy for people with disability.[145] This is an area that we will be considering further.

We have heard that there are few disability advocacy services for First Nations people with disability. Some First Nations organisations have told us that they provide unfunded advocacy as part of their commitment to speaking up for community members with disability, such as in health, childcare, domestic violence and legal matters.[146] Disability services have said that the lack of funding and resources for First Nations disability advocacy limits what they can do to create better services and support for First Nations people with disability in their region.[147]

Through our inquiry, we will continue to look at how representation and advocacy may both help prevent and better respond to violence against, and abuse, neglect and exploitation of, people with disability.

Oversight and complaints

Oversight and complaints mechanisms are essential to preventing violence against, and abuse, neglect and exploitation of, people with disability, and ensuring appropriate responses when they occur. Our terms of reference require us to inquire into best practice in 'reporting of, and effective investigations of and responses to, violence against, and abuse, neglect and exploitation of, people with disability', including barriers to reporting and investigating.[148] In Australia, each state and territory has primary responsibility for systems and services provided within their jurisdiction.

The NDIS Quality and Safeguards Commissioner (NDIS Commissioner) is responsible for regulation and oversight of services and supports provided for people with disability under the NDIS. This includes the national provider registration process, NDIS Practice Standards and the NDIS Code of Conduct.[149] The NDIS Commission will also coordinate the NDIS Worker Screening Check as a single national clearance for workers in both registered and unregistered providers.[150]

We have been told by people with disability, family members, advocates and disability workers that they have experienced incidents that have been minimised, ignored or gone unreported.[151] Women with Disabilities ACT noted that minimising complaints can affect access to justice:

> Many bodies that do handle complaints treat group homes as institutional or service environments and treat criminal incidents as service incidents. This makes it extremely difficult for women with disabilities in these settings to seek help and pursue justice.[152]

Advocates and organisations have also made similar representations about the experiences of their clients. The Sexual Assault Support Service Inc said: ‘Put simply, people with a disability who disclose abuse are often not believed.’[153]

WWILD Sexual Violence Prevention Association stated that people with intellectual disability are ‘less likely to understand their rights and how to enact them’ and are ‘less likely to have an understanding … of police processes’, which creates barriers to reporting.[154]

We have also heard that some people with disability have been punished for making complaints about the care or services they are receiving.[155] Some people described being afraid; one woman with disability told us she ‘never complained to the care organisations due to my fear of retribution’.[156]

Speech Pathology Australia told us that inaccessible complaint procedures can be harmful for those who are non-verbal or deaf.[157] The Australian Sign Language Interpreters Association Inc gave the example of a Deaf student wishing to make a complaint about the person who interprets for them, but only being able to do so through that interpreter.[158] We have heard that complaints made by people with disability, particularly those with psychosocial or intellectual disability, are not always taken seriously,[159] or are considered ‘minor’.[160]

We have heard that it can be difficult for students with disability and their parents to make complaints and have violence, abuse and neglect acknowledged and resolved. Reporting and investigation processes are often not accessible, trauma-informed or adaptive to the needs of children and young people with disability.[161] We have also heard that reporting processes can be insufficiently independent and that education departments often refer complaints back to the school for investigation with little oversight.[162] One family, describing the complaints procedure at their child’s school, said ‘[a] system that relies on institutions reporting themselves is inherently set up to cover up and perpetuate the abuse’.[163] The family also described challenges faced in the Catholic school system and said that the lack of independent oversight is compounded by the system not being regulated in the same way as the public education system.[164]

Simon and Alice*

Simon has physical and intellectual disability. In the early 2000s he worked in a disability enterprise, which he loved. He had friends there and it was important to his mental health. Simon's sister, Alice, told us how that ended one day, when he was raped by one of the workers.

In her submission, Alice describes what happened next. She reported the attack to the police. Simon was interviewed by the sexual assault unit and by a psychiatrist, who confirmed that Simon's behaviour was consistent with having been raped. Alice says she also reported the attack to the management of the disability enterprise, who acknowledged that something had happened to Simon but did not use the word 'rape'.

When Simon told his family what happened and recounted it again when they reported it, he had to relive the trauma. However, Alice told us the police did not proceed with the charges as there were no witnesses to the rape and the prosecutors said Simon would not make a good witness at trial.

Simon would not return to the disability enterprise. Since the rape, Alice said, he's been scared of men and difficult to take out. He no longer has contact with his friends from the disability enterprise and has spent 10 years socially isolated in his room.

Alice said the disability enterprise never followed up with Simon or offered him a position anywhere else. 'We were totally disappointed at the lack of care and concern expressed for Simon when this awful thing happened to him.'

Simon was offered a position at a different disability enterprise a decade later when Alice got the local member of parliament involved. But he was unable to interact with the other people there as he was afraid of men and physical contact. He was scared both at the disability enterprise and on the bus getting there, Alice said. He stopped going there and now relies on a female carer to take him out.

Alice told us she believes that Simon was raped because of his physical and intellectual disability and because his attacker didn't think that Simon would be able to report the attack or that people would believe him.

'Our concern is that the rapist faced no consequences. He had the ability to continue and perhaps next time rape somebody who cannot speak,' she said.

Alice said:

> Disabled people need to be believed when they tell us about abuse and violence, and special allowance needs to be made in courts so the perpetrators can be brought to justice.

*** Names changed and some details removed to protect people's identities. Narrative based on a submission to the Royal Commission.**

We have been told about a range of issues related to complaints mechanisms within the health system, including that they are inadequate, inaccessible or otherwise ineffective.[165] A submission from the Royal Australian College of General Practitioners suggested that violence against, or abuse, neglect or exploitation of, people with disability in the health system may not be reported because of:[166]

- a poor understanding of the signs of violence, abuse, neglect or exploitation
- uncertainty and limited guidance about how to report abuse, including difficulties understanding appropriate reporting channels
- a lack of alternative health care options
- communication barriers
- limited support for people with disability to report.

Access to complaints processes can be limited in group homes, boarding houses and short-term accommodation. One person with disability explained how the complaints process at her group home was not private or confidential, which discouraged her from making a complaint:

> [they] brought in a new computerised complaint system over the last 2 years. The only way I can access this was to have a staff person scribe for me as the staff computer does not have the accessibility software installed (onscreen keyboard through windows). This means my complaints were not confidential.[167]

During Public hearing 4, Jayne Lehmann, the Director of EdHealth Australia and parent of a child with intellectual disability, expressed concern that the NDIS Commission quality and safeguards complaints process was inaccessible to people with intellectual disability. She said, ‘even the service that is designed specifically for the needs of people with intellectual disability … [is] not providing an accessible way for them to complain’.[168]

We have also received information about a lack of internal supervision and external oversight in some day programs.[169] We will continue to explore day programs through our ongoing work.

The Royal Commission will also continue to examine how oversight and complaint mechanisms function, as part of our investigation into reporting of and responding to the violence, abuse, neglect and exploitation experienced by people with disability.

Data

There is a lack of data on the violence, abuse, neglect and exploitation experienced by people with disability across all sectors and settings.

Addressing this gap is critical, as high quality data is essential to inform and assess government policies that affect the lives of people with disability. This is discussed in more detail in Chapter 15, ‘Nature and extent of violence against, and abuse, neglect and exploitation of, people with disability’.

The best publicly available data on violence against people with disability is the Australian Bureau of Statistics *Personal Safety Survey*. However, this survey does not include whether people with disability identify as First Nations or lesbian, gay, bisexual, trans and gender diverse, intersex, and queer and questioning (LGBTIQ+), reflecting the lack of data available for some groups of people with disability.

While Australia collects statistical information on the number of people with disability, there is no publicly available data on the extent of violence, abuse, neglect or exploitation experienced in settings such as schools, residential out-of-home care, the criminal justice system, or segregated workplaces. Examples of data gaps in specific settings are described in more detail in Chapter 15 and include:

- no national data on violence, abuse, neglect or exploitation, including use of restrictive practices, experienced by children with disability in schools
- no disability identifier in Australian medical data, such as hospital data and pharmaceutical benefits scheme data
- no data on reports or allegations of violence, abuse, neglect and exploitation in the provision of disability services that sit outside the jurisdiction of the NDIS Commission (including on unregistered service providers, specialist disability services funded under an in-kind arrangement by states or territories, and incidents involving people who are not NDIS participants).

There is limited publicly available data on outcomes and outputs, or the indicators used to measure outcomes, for the programs, services and systems funded by governments. This makes it very difficult to track, monitor, analyse and evaluate the effectiveness of governments and institutions' policies and actions that impact on the lives of people with disability.

The Royal Commission will continue to investigate data gaps and identify areas where the lack of data hinders the development of evidence-based policy and practice. Chapter 15 outlines three ways we will investigate and address data gaps.

Funding

We have heard about funding and its impact on access to support and services for people with disability, and about how funding structures can create disincentives, conflicts of interest and potentially poorer outcomes for people with disability.[170]

The Royal Commission has heard that changes to how funding is structured could lead to better prevention against, and protection of people with disability from, violence, abuse, neglect and exploitation, and assist with better reporting and responding.[171]

Issues raised in the context of education include:

- a lack of funding to support students with disability and inappropriate use of funds within schools[172]
- parents being required to self-fund support[173]

- inconsistent access to funding and support across jurisdictions and education systems.[174]

Some submissions have called for more funding and resources for education settings.[175] Others have said that the structure of federal funding means that students in special/segregated education settings attract a greater proportion of funding, which channels resourcing and expertise into these environments rather than mainstream education settings.[176]

We heard about the structure of funding for group homes under NDIS frameworks at Public hearing 3.[177] Witnesses gave evidence that people living in Specialist Disability Accommodation (SDA) funded group homes may not have a choice over who their Supported Independent Living (SIL) provider is, as all residents have the same provider.[178] Ms Kayess explained that:

> If residents in [a group home] have a dominant agency that they use for the provision of care, whether it is being provided by the agency managing the group homes, if somebody else moves into that group home and wants a different agency, nine times out of 10 they won't get that choice.[179]

Disability research Dr Ilan Wiesel noted that in some instances:

> Once [people with disability] enter a group home … the support provider is both their landlord, they run the home in which they live but also their support provider … And that creates a power dynamic that is – is very much against the residents. … They have quite significant control over your life.[180]

Leanne Pearman, Co-Chief Executive of Western Australian Individualised Services, noted that the lack of separation between service providers and accommodation providers can create a power imbalance:

> As people are supported and, historically, have been supported by providers that have provided the total care and support for them over many decades … there is a sense of ownership at times.[181]

As we continue our investigation, we will examine these emerging themes, and any others that arise, to understand their effects on the violence, abuse, neglect and exploitation experienced by people with disability.

Key issues

Through public hearings, submissions, community engagement, private sessions, research and responses to issues papers, we have heard about a number of key issues across systems, services and domains. Many of these are discussed in existing research and academic literature, as well as in our research program. Issues have been raised in the context of:

- education and learning
- homes and living
- relationships
- health care
- community participation
- economic participation
- the NDIS
- the justice system.

We have also heard about the experiences of people with disability during the COVID-19 pandemic.

These key issues are often connected to the emerging themes described above. Violence, abuse, neglect and exploitation experienced by people with disability is not limited to discrete settings or contexts but may be the result of systemic failures across multiple areas. Through our ongoing work we will explore the association between these failures and the wider exclusion of people with disability from society.

Education and learning

> School was supposed to be a place of feeling safe and supported.[182]

While the Royal Commission has received information about experiences of violence, abuse and neglect across all stages of education, many contributions so far have focused on primary and secondary education. The emerging picture is that not all students with disability in Australia receive the same quality of education as students without disability. This may have negative long-term impacts on employment, health, independent living and healthy relationships.

What is clear from the information provided to us so far is the desire for real and lasting change in education for students with disability.

> If nothing else, I would like to think that maybe, after this commission, no other child has to go through their schooling battling for recognition as … [a] functioning member of society.[183]

Access to education

We have heard about the lack of access people with disability have to education, its opportunities and benefits. This includes barriers to enrolling in school, limited opportunities for development, and a lack of reasonable adjustments, supports and planning within the education system.[184] We have also heard about the exclusions experienced by students with disability, including disproportionate use of suspensions and expulsions.[185]

One person with disability described how teaching staff presumed he 'did not comprehend what was required and expected from a high school student … It was a message to me that I shouldn't be there'.[186] A parent told us that their child with disability had been:

> threatened with suspension (grade 2), made to pick up the classes rubbish when they couldn't draw neatly (grade 3), told every week for a wh[o]le term to just play games on the laptop because 'what's the point' (educating them) (grade 5), and kept in at lunch and recess countless times.[187]

The Australian Centre for Disability Law provided us with a number of examples relating to a lack of reasonable adjustments and supports for students with disability. They described the experience of one family who reported that their complaints about the lack of reasonable adjustments were unsuccessful and that their child now faces additional years of schooling and a difficult relationship with the school.[188]

Children and Young People with Disability Australia told us about how restrictions related to COVID-19 have exacerbated existing barriers to education or created new ones for students with disability.[189] For example, one parent of a child with disability told us, 'this current mode of [online] education delivery has left her more confused and distressed. She is someone who cannot learn at home but yet she is not able to attend school.'[190]

Violence and abuse in education settings

We heard about incidents of physical, verbal and emotional violence and abuse in education settings. A family shared their sons' experiences:

> Our sons have sustained 80 (eighty) injuries at that school including 24 head injuries, multiple cases of severe sunburn, multiple cases of insect swarm bites and stings, multiple cases of obvious physical violence from staff, multiple cases of obvious strap, rope and cane welts on their arms, legs and back, several cases of heat stroke … I witnessed a staff member attack my son with her fists. Various staff have admitted to 3 witnesses that they have repeatedly locked one son out of the classroom, let him stuff plastic bags in his mouth and said 'Disabled children don't feel pain.' … We are disgusted and terrified at the complete lack of compassion and humane treatment of our little sons.[191]

We also heard about restrictive practices being used on students with disability. We were told about children with disability being locked in cupboards, bathrooms, offices and classrooms, alone and without educational materials.[192] We have been told of schools asking parents to medicate their children to address behaviours of concern.[193] Submissions have also talked about physical restraint. One described such severe bruising on a child's wrists from being restrained that he could not lift them.[194]

Safe, quality and inclusive education

We have also been told about what people and organisations see as the key factors for safe and quality education. These include:

- strong leadership[195]
- inclusive culture[196]
- effective workforce training[197]
- collaboration between students, parents and educators[198]
- accessibility[199]
- provision of adjustments and supports.[200]

In its response to our *Education and learning issues paper*, the Australian Human Rights Commission recommended integrating training on inclusive education and disability awareness across all educational degrees and diplomas at Australian universities and vocational education and training institutions, as a means of achieving inclusive education.[201]

We have heard different perspectives about the best way to structure Australia's education system.

Some students with disability are educated in 'separate environments designed or used to respond to a particular or various impairments, in isolation from students without disabilities'.[202] As noted earlier, the CRPD Committee refers to this as segregation. In Australia, schools, classes or units for students with disability are often called 'special' schools, classes or units. All state and territory education systems include special/segregated education settings, as a parallel or dual system. We have heard from some parents of students with disability, educators, organisations and associations representing special education who hold the view that special/segregated education settings can differentiate education, adapt curriculum, provide specialist support and cater to diverse needs.[203]

We have also heard a different view from some people with disability, parents of students with disability, teachers, peak organisations and academics, who endorse inclusive education and believe there is a link between special/segregated education and higher rates of violence, abuse and neglect, both in these settings and later in life. Some organisations and academics describe these settings as based on an understanding of disability as deficit.[204] Many organisations have told us that this perpetuates the exclusion of people with disability, as students rarely transition into mainstream education.[205]

All Means All said that disability-based segregation of students has life-long impacts, including by creating:

> the ongoing dependency on segregation services – one site of confinement leading to another. Institutionalisation from cradle to grave that used to occur in the large institutions has become the segregated ‘pipeline’ of segregated ‘early intervention’, segregated schooling, ‘sheltered workshop’ and ‘group home’.[206]

These organisations, along with some people with disability and their families, have called for a national inclusive education strategy and action plan, based on Article 24 of the *CRPD* and the CRPD Committee’s concluding observations.[207]

A summary of the themes emerging from the evidence presented at Public hearing 2: Inclusive education in Queensland – preliminary inquiry, is discussed in Chapter 12. A detailed report of Public hearing 2 is available on our website.

Through our inquiry, the Royal Commission will continue to examine:

- the nature and extent of violence, abuse, neglect and exploitation across different education settings
- the factors that drive or contribute to it
- what structural changes are needed to education systems across Australia to better protect students with disability from violence, abuse, neglect and exploitation.

Franklin*

> **They thought my disability was my lot in life and … that basic necessities of education would suffice for me … I believe they thought the assaults, humiliation and harassment were part and parcel of the hurdles I had to conquer alone.**

Franklin has a neurodevelopmental disorder, which includes motor and vocal tics. In his submission he told us that at school he was regularly harassed and assaulted.

Franklin told us that students would torment him by saying he was gay and calling him names related to his disability. Then the kids started cyberbullying him on Snapchat. The harassment and humiliation intensified 'akin to a blowtorch'.

Franklin told us that he lashed out and was suspended.

> The institution blamed me and poor choices I made for everything that happened … However, I felt the school was trying to use my behaviour to justify their negligence in failing to provide me a safe schooling environment free from discrimination in the spirit stipulated by the Disability Standards.

Franklin's dad complained to the school several times, and tried to get the school to provide an individual adjustment plan under the *Disability Standards for Education 2005* (Cth) to support Franklin. But the school wasn't interested.

Franklin believes that the school never complied with the Disability Standards:

> I think my previous school and the governing body did not believe they were legally obliged to comply with the Disability Standards because I am not severely physically or intellectually incapacitated.

In his senior years, Franklin said, the school tried to restrict his access to particular subjects. His parents decided to move him to another school, despite the disruption.

Franklin is now free to study the subjects he chooses and has an annually reviewed independent learning plan:

> Changing schools literally saved my life because I was at risk … My current school complies with the Disability Standards and I feel safe, welcome and socially and educationally supported in that environment. I feel like I am now thriving …

*** Name changed and some details removed to protect people's identities. Narrative based on a submission to the Royal Commission.**

Homes and living

Everyone has the right to feel safe at home and a person's home is central to their life, independence and wellbeing. However, data from the Australian Bureau of Statistics shows that people with disability are more likely to feel unsafe in their homes than people without disability.[208]

In Australia, 96 per cent of people with disability reside in private homes and almost 4 per cent live in supported accommodation, which includes specialist disability accommodation and aged care.[209] Some people with disability live in short-term accommodation, or experience unstable housing or homelessness.[210]

The 2015 Senate committee inquiry into violence, abuse and neglect against people with disability in institutional and residential settings reported that 'where people with disabilities live and the cultures of the organisations that provide services, in particular residential services, are significant factors that impact on risk of violence, abuse and neglect'.[211]

We have heard about experiences of violence, abuse, neglect and exploitation across the range of residential settings. Our early work on homes and living has focused on group homes. An outline of the themes that emerged from the evidence we heard at Public hearing 3 is discussed in Chapter 13, 'Public hearing 3: The experience of living in a group home for people with disability'. A detailed report of Public hearing 3 is available on our website.

Unsafe living arrangements

> She was hit, pushed, spat upon and had her property constantly stolen both by workers and other co-tenants.[212]

We have heard about violence against, and abuse, neglect and exploitation of, people with disability in private homes. For example, one submission described the experience of a woman with disability who lives with her brother in a private home but is isolated by her brother, not supported to attend NDIS appointments, financially exploited, and lives in unclean surroundings.[213] In the context of violence, abuse and neglect experienced by people with disability in private homes, previous reviews have proposed expanding the role of community visitors to private homes where support services are provided.[214]

We have also been told about some people with disability having unexplained injuries and experiencing neglect in supported accommodation. The lack of skill development for residents in supported accommodation has also been raised, and described as 'abuse by omission'.[215] In its response to the *Group homes issues paper*, Independent Advocacy SA Inc told us that 'life in a group home often means a life of supported dependence'.[216]

The standardisation of care provided to people with disability in some supported accommodation facilities has been described as neglect.[217] Women with Disabilities ACT told us that the preferences of women with disability living in group homes, such as a preference to work with female staff, were 'ignored as a matter of convenience' and this could elevate the risk of violence and abuse.[218]

Australian disability researchers Professors Sally Robinson and Lesley Chenoweth argue there is an imbalance of power in disability services, which 'perpetuates a climate that is ripe for abuse'.[219] We have been told about abuse by people in positions of power in residential settings. For example, the parent of a child with disability told us that their son was sexually abused in short-term accommodation by a person in a position of authority and that it 'caused complex trauma'.[220]

The Royal Commission has also heard the nutritional needs of some people with disability are being neglected, impacting their health and wellbeing.[221] For example, a person with disability described instances of not being fed or given drinks while residing in a group home.[222]

Barriers to safe and independent living

We have received information about the barriers to independent living confronting people with disability. Research suggests that living independently in the community, with quality, well-supervised support, can contribute to a number of positive outcomes. These include increased autonomy,[223] improved community participation,[224] greater independence and control over personal decision-making, choices and finances.[225] Following the recent death in Adelaide of Ms Ann Marie Smith, the interim report of the South Australian Safeguarding Task Force highlighted the importance of oversight through 'proper supervision of support workers by the service provider agency'.[226] The taskforce also highlighted the critical role that support networks and supportive relationships can play in safeguarding against harm.[227]

Attitudinal barriers can prevent people with disability from independent living. For example, one submission from an advocate described how a person with disability felt that despite multiple planning discussions for future independent living, 'others are not allowing him to live by himself'.[228]

We have also been told that a lack of housing options forces some people with disability to live in supported accommodation or inappropriate housing.[229] This particularly affects First Nations people and people from rural and remote communities.[230]

As discussed in Chapter 1, 'Why this Royal Commission is needed', until the late 20th century many people with disability in Australia were segregated in large residential institutions. A trend towards de-institutionalisation began in the 1960s and many large residential institutions had closed by the 1980s.[231] At Public hearing 3, Dr Wiesel described 'clusters' of new residences on the sites of former institutions, and that 'many disability rights organisations objected to the development of such a cluster, on the basis that this will reproduce some of the same problems that existed in the institution'.[232] Some submissions suggest that institutional cultures and practices persist today, despite policies of de-institutionalisation.[233]

Throughout our ongoing work we will consider how homes and living arrangements can support the independence of people with disability and their right to live free from violence, abuse, neglect and exploitation.

Relationships

Everyone has a right to family, and to be free from violence and abuse in relationships.[234] The Royal Commission has received information about the experiences of people with disability of domestic and family violence, sexual violence, child removal and child relinquishment. Many people have shared stories of being subjected to multiple forms of violence and abuse in relationships.

Domestic, family and sexual violence

People with disability experience higher rates of domestic and family violence than people without disability.[235] More than one-third of women with disability (36 per cent) have experienced violence by a current or previous partner, compared with one in five women without disability (21 per cent).[236] Fifteen per cent of men with disability have experienced partner violence in their lifetime, compared with 7 per cent of men without disability.[237]

People with disability can experience a variety of different forms of domestic and family violence, including withholding of food, water, medication or support services, use of medical or physical restraints, control of reproduction, and forced isolation as well as physical and emotional violence and abuse.[238]

We do not know rates of intimate partner violence for First Nations people with disability or culturally and linguistically diverse people with disability. However, the AIHW reports that in 2016–17, First Nations women were 34 times more likely to be hospitalised due to family violence than non-Indigenous women.[239] For First Nations women, a spouse or domestic partner was reported as the perpetrator for hospitalisations in 62 per cent of cases.[240] First Nations women in remote areas are more likely to be hospitalised due to family violence than First Nations women in urban areas.[241]

Research has shown that the risk of domestic and family violence can increase in times of crisis.[242] We have heard that during the COVID-19 pandemic, people with disability experienced increased isolation as a result of restrictions.[243] This may have meant that people with disability have had less access to support networks and been less able to report and escape domestic and family violence.[244]

As well as violence from intimate partners, we are also hearing about violence or abuse by other family or kinship network members and support workers. For example, one submission from a man with disability described being sexually abused as a child by extended family members.[245] Submissions have also described violence from support workers in residential settings. One woman told us about her brother being beaten, burned with cigarettes and medicated by staff in a children's home.[246]

Research from the Centre of Research Excellence in Health and Disability suggests that in a 12-month period, women with disability are twice as likely (32 per cent) to experience sexual violence than women without disability (16 per cent).[247] Men with disability are also more likely to experience higher rates of recent sexual violence (9 per cent) than men without disability (4 per cent).[248]

Child removal and relinquishment

The Royal Commission has received information about circumstances in which children have been removed from a parent or parents with disability.[249] For example, one mother with disability told us during a community forum that child protection authorities said, 'Sorry, you can't have your children, because you're not good enough to do it.'[250] We have also heard from adults with disability about being removed from family when they were a child.[251]

In one submission, a First Nations mother with disability told us the police said that 'deaf people should be sterilised and should not have children … I was clearly seen as incapable and neglectful because of my disability.'[252] Data from the AIHW indicates that First Nations children are removed at 10.2 times the rate of other children.[253] First Nations representative groups say that historical and current practices of child removal are in part responsible for mistrust of mainstream systems, resulting in First Nations families being less likely to access supports.[254]

The Royal Commission has received submissions that raise concerns about the removal of children from parents with intellectual disability.[255] For example, Developmental Disability WA told us there is a lack of specialist parenting support and that no disability-related adjustments are made for parents with intellectual and cognitive disability when dealing with child protection processes.[256]

Some parents have made submissions to the Royal Commission about relinquishing their children with disability to state systems.[257] They have told us about a lack of support to continue caring for their family member at home, being pressured by providers to relinquish their children, and their children being abused in care.[258]

Throughout the course of our inquiry we will examine the nature and extent of violence against, and abuse, neglect and exploitation of, people with disability in the context of relationships, including abuse related to sexual and reproductive rights, and violence between people with disability. We will also inquire into the barriers to parenting experienced by people with disability, and the roles of families and carers.

Health

People with disability and families have told us about their experiences accessing health care, and the challenges they can face getting the care they need. We also heard about violence and abuse in health care settings and people with disability experiencing involuntary treatment and diagnostic overshadowing (when a person's medical symptoms are misattributed to their disability, as explained later in this chapter).

Some of these issues were examined in detail at Public hearing 4, and are discussed in Chapter 14, 'Health care and services for people with cognitive disability', which summarises the public hearing. A detailed report of Public hearing 4 is available on our website.

Access to quality health care

People with disability report poorer health than people without disability. According to the AIHW, people with disability are six times more likely to rate their health as fair or poor (42 per cent) than people without disability (7 per cent).[259] They are four times more likely to self-report high or very high levels of psychological distress (32 per cent, compared with 8 per cent).[260] Some studies indicate high death rates and low life expectancy for people with intellectual disability, particularly for women with intellectual disability.[261]

The Queensland Aboriginal and Island Health Council has told the Royal Commission that First Nations people 'face significantly disproportionate health challenges compared with those faced by other Australians'.[262]

In 2019, the CRPD Committee commented that in Australia:

> compared to the general population, persons with disabilities, in particular persons with disabilities living in remote areas, Aboriginal and Torres Strait Islander persons with disabilities, persons with intellectual or psychosocial disabilities, persons with disabilities living in institutions and children and women with disabilities, are in significantly poorer health and have less access to information and to adequate, affordable and accessible health services and equipment.[263]

A First Nations woman who is Deaf told us that she was turned away by doctors as she did not look 'sick enough', despite making a number of appointments and waiting a considerable time.[264] She said she had requested an interpreter but later found out that the doctor's surgery did not want to pay for an interpreter, nor did they want to see her without one.[265] She told us that after attending a different clinic, she was diagnosed with cancer:

> I was diagnosed with stage three breast cancer. Unfortunately, it had already spread throughout my system. So, now I have liver cancer. I've had cervical cancer. And I have ongoing chemotherapy. But, for me, if I had had early access, potentially, it would have prevented me from having the complications and the metastatic issues that have happened with my cancer, that have travelled throughout my body.[266]

We have heard about a range of barriers that people with disability face when accessing health care, as discussed earlier in this chapter, in 'Barriers to accessing services and supports'.

We have been told in submissions about health professionals who appeared reluctant to treat patients with disability. This has been described as being due to perceptions about the value of people with disability, people with disability being regarded as difficult and time-consuming, or perceived financial disincentives to treating people with disability.[267]

The Royal Commission has been told about health staff not listening to patients with disability or talking about them rather than to them. For example, Speech Pathology Australia described an incident where a Do Not Resuscitate order was placed on a person with disability in intensive care without the doctors consulting the person with disability or their family. They said this was due to the doctor's belief that the 'quality of life was poor'.[268]

We have received submissions from people who told us that the health care needs of some people with disability in supported accommodation may be neglected. For example, one response to our *Health care for people with cognitive disability issues paper* described a person with cognitive disability not receiving medical care apart from visits to the GP for five years, despite requiring other services, while in residential care.[269]

People with disability have faced difficulties in accessing health care during the COVID-19 pandemic.[270] Children and Young People with Disability Australia told us that the transition of face-to-face services to online telehealth was 'problematic' and increased the inaccessibility of health care during the pandemic for some.[271] Vision Australia highlighted the challenges for people who are blind or have low vision in accessing testing facilities, relaying the experience of one person:

> I had a telehealth appointment with my GP and was told I needed to get tested for COVID-19. I was told my nearest clinic was a drive through clinic however I cannot drive because of my vision. Government advice is that you do not take rideshare taxis or public transport if you're suspected of having COVID-19. I didn't want to expose my friends or family who don't live with me by making them drive me to a testing centre.[272]

Oliver and Petra*

‘Does it really matter if your son can’t hear?’

In her submission to us, Petra said a surgeon asked this question about her son, Oliver, who has Down syndrome and needed grommets in his ears. When Petra told him it mattered a great deal, the surgeon said Oliver would be ‘at the bottom of the list … because he had a disability’.

For seven years Oliver saw an optometrist who said his eyesight was fine. But, in reality, Oliver was legally blind and should have been wearing glasses at 12 months.

No wonder he hadn’t been able to write, Petra said – the letters were fuzzy. The teacher thought Oliver was being naughty, but he lacked the verbal skills to explain what was happening. ‘He lost so much at school which has impacted his education to this day,’ Petra told us.

These incidents demonstrated to Petra that ‘advocacy is needed so badly for the person with a disability’. It took another incident to convince her that the carer of someone with disability also needs an advocate.

Oliver woke up one morning with a stiff neck. When pain relief didn’t help, Petra took him to their GP. He suggested they consult their regional hospital – a 45-minute drive away.

Oliver was admitted, given an X-ray, told everything was fine and discharged ‘with a tube of Dencorub … the problem would resolve itself over time’.

He didn’t improve and needed help standing and lying down. Petra also noticed he stopped breathing for a few moments before starting again.

The GP organised an appointment with a sleep clinic at the major children’s hospital several hours’ drive away.

At the appointment Petra mentioned Oliver’s sore neck and the doctor said he would have a neurologist take a look. It was too painful for Oliver to lie down for a CT scan, so he had an MRI under sedation.

The MRI revealed a ‘subluxation of the C1/C2 of the spine. The C1 had rotated and fallen off the plane of the C2’. This meant that if Oliver had fallen over in the preceding few weeks he would have died. The neurologist told Petra it was the worst case he had ever seen.

The hospital doctors reviewed Oliver's case and decided not to operate. They told Petra to take him home 'even though we were told that any sudden movement in a car or a fall could result in death'.

Petra rang the GP, who contacted the hospital and said that if anything happened to Oliver it would be the hospital's responsibility.

A junior doctor at the hospital approached Petra and suggested she contact a neurosurgeon who operated at a nearby private hospital and the children's hospital.

The neurosurgeon agreed to operate on Oliver at the children's hospital and, despite having an 18-month waiting list, scheduled Oliver's surgery in three weeks. Until then, Oliver had to stay in the city, 'be kept still and not travel in a car, only to get to hospital for the operation'.

The operation didn't go smoothly, Petra recalled, because the delays meant Oliver's neck 'had locked in place'. When the nurses tried to wake him up from the anesthetic, he didn't understand what was happening and started thrashing around. It took Petra two hours to convince them that Oliver was frightened and they needed to bring him around with medication. Eventually they listened and did so, but then they refused to listen about pain relief.

The nurses decided Oliver wasn't in significant pain and could be given Panadol, Petra told us. She explained to them that Oliver couldn't swallow tablets and was in severe pain and needed IV medication. It took the doctor's intervention to make this happen.

'Over the course of the next [seven] days I found the nurses treated [Oliver] completely differently than the other children.'

Petra would like to see better supports for carers in the health system. She says advocacy is needed not only for the person with disability but also for their carer.

She described having to fight constantly for Oliver to be treated equally, and said there have been too many times when she felt unsupported and alone.

*** Names changed and some details removed to protect people's identities. Narrative based on a submission to the Royal Commission.**

Diagnostic overshadowing

We have also heard about experiences related to diagnostic overshadowing.

At Public hearing 4, Professor Julian Trollor described diagnostic overshadowing as ‘a misattribution of symptoms of physical or mental illness to the disability, rather than to the problem that’s caused them’.[273]

Dr Avery also gave evidence at Public hearing 4 that ‘a person’s disability “overshadows” the underlying health conditions as the diagnosis is biased by the clinician’s presumptions and preconceptions about disability’.[274] Diagnostic overshadowing can result in delayed or misdiagnoses of serious medical issues.

In one submission, a mother told us of an incident where her daughter with Down syndrome was choking on a piece of bone. She said the doctor at the emergency department dismissed her daughter’s condition as ‘drooling’ due to her disability and wanted to send her home. Her daughter eventually received surgery to remove the bone.[275]

Dr Avery also gave the example of a First Nations man with quadriplegia who was experiencing hyperthermia due to a hot day and went to an air conditioned bottle shop that sold ice to cool down. Dr Avery stated, ‘when the ambulance turned up, he was passed off as being drunk’.[276] Dr Avery highlighted that diagnostic overshadowing is not just a communication issue between doctor and patient, but an example of ‘institutional prejudice that sits within the health care system’.[277]

Data from the AIHW suggests people who experience discrimination on the basis of disability in the health sector are four times more likely to avoid medical facilities as those who have not experienced discrimination.[278]

Involuntary treatment

Some people with disability have told us about their experiences of involuntary medical treatment, particularly mental health treatment, which they described as leaving them traumatised. We have heard about:

- electroconvulsive therapy used against a person’s will[279]
- medication used without consultation or informed consent[280]
- use of police to enforce involuntary treatment[281]
- chemical sedation without therapeutic benefit[282]
- seclusion[283] and physical restraint[284] to manage mental health concerns
- threats of involuntary treatment orders if people question medical practice and ask for more information about treatment[285]
- suggestions that some women with disability in group homes are subjected to forced contraception.[286]

While comprehensive data on the number of people with disability subjected to involuntary treatment is not publicly available, statistics from the AIHW indicate that across Australian acute care settings in 2017–18:[287]

- 44 per cent of discharges after a mental health admission had involved involuntary treatment
- 57 per cent of patient days for mental health treatment were for involuntary treatment
- 15 per cent of community mental health care service contacts were with people receiving involuntary treatment.

We will continue to work to understand the nature and extent of violence, abuse, neglect and exploitation across different health care settings, as well as the systemic factors that drive or contribute to these experiences and what changes may be needed to achieve access to quality health care for all people with disability.

Community participation

Participating in the community is about the relationships we form, our engagement in civic life and our sense of belonging. People with disability continue to confront barriers that prevent their full and equal participation in the community. We have heard about environmental, communicative, institutional and attitudinal barriers.

Accessibility is essential for people with disability to live independently and fully participate in society on an equal basis with others.[288] People with disability are excluded from society when spaces, places and information are not accessible. A research project undertaken for the Royal Commission found a strong association between safety and the accessibility of environments for some people with disability.[289] Participants with cognitive disability discussed experiences of safety in terms of the physical environment, such as on the road or in the water, while Deaf participants associated safety with access to information.[290] One Deaf research participant said:

> For Deaf people, it’s also about access to information, being able to communicate with people. That makes me feel safe, and you’re much less vulnerable if you have that access.[291]

People with disability have told us that they often experience physical barriers when accessing buildings and environments. One participant at a community forum in Logan, Queensland, told us that access to buildings is ‘the tip of the iceberg’ of the barriers faced by people with disability and that ‘including people into buildings is important because it includes them in our society’.[292] Another person told us in a submission how barriers that prevent physical and social access to community events can leave people feeling as if they ‘lived in a prison’.[293]

Accessible information and communications are also essential for the inclusion of people with disability in society and to ensure their safety, especially during emergencies.[294] The *Disability rights now 2019* report stated that more than two-thirds of people with disability find government information inaccessible or difficult to understand.[295] As noted earlier, this report also says that the challenge of accessing information can be heightened for people with disability from culturally and linguistically diverse backgrounds when information is only provided in English.[296]

A number of organisations highlighted the challenges created by requirements for social distancing and lack of clear information during the COVID-19 pandemic.[297] Children and Young People with Disability Australia have told us how access to information has been unreliable and confusing during the pandemic.[298]

AED Legal said:

> Many people with disabilities feel as if they have been overlooked. Lack of information available to people with disabilities has meant that they are often the last to be educated about the risks associated with the state of emergency. A lack of assistance within a state of emergency greatly impacts people with disability and makes them vulnerable to neglect and exploitation. Social distancing is impossible for many who rely on the support of others for their basic needs. A lack of assistance in helping people with disabilities to respond to a state of emergency can leave them vulnerable and left behind.[299]

We will consider how participation in the community relates to more inclusive societies that support the independence of people with disability and their right to live free from violence, abuse, neglect and exploitation.

Sam*

In their submission Sam told us they have multiple disabilities, including autism, depression, anxiety and functional neurological disorder (FND). These disabilities affect their life in many ways. Sam 'has constant low mood and chronic suicidal thoughts' and problems communicating, making decisions and interacting with others. The FND affects their mobility, but 'I can walk moderate distances using mobility aids'.

Sam has experienced significant neglect and abuse from mental health professionals. Sam has been 'misdiagnosed and had diagnoses missed due to diagnostic overshadowing' – that is, where physical symptoms are misattributed to psychosocial symptoms. Sam has been 'talked down to and ignored'. Some medical professionals have 'actually refused me care due to my autism'. One time they were told 'I was only hallucinating because of my autism' and they were 'discharged from the public mental health service I was accessing'.

Another time Sam was an inpatient in hospital. As soon as the medical professionals saw them using a cane 'that was all they focused on, despite me being there due to depression.' They were told 'there was nothing wrong with me, other than FND, and my depression was just in my mind.' The psychiatrist threatened to discharge Sam and Sam 'expressed concerns for my safety'. The psychiatrist then told Sam they were not a suicide risk.

That night in the hospital room, 'I was about to attempt it but was interrupted by a nurse.' The next day Sam was discharged without being treated and told to 'find (and pay for) a private autism specialist'.

Before being diagnosed with FND, Sam said they 'couldn't walk as far or as fast as my grandmother, and was in constant agony'. Sam was told 'not to get a mobility aid because "I would look disabled"'.

Sam would like to see 'massive changes in how doctors and other people in the medical profession view disability' and said they should be 'made aware of and trained on avoiding diagnostic overshadowing'.

Some of the doctors Sam spoke to were completely unaware of the existence of overshadowing. 'Often I know more about my conditions than the person treating me, making it even more frustrating when I am talked down to.'

Sam told us they believe that doctors are more likely to 'dismiss physical issues when someone has co-morbid issues' resulting in 'near complete lack of care'. Sam would also like to see mental health services made accessible for autistic people. 'We simply need the same quality of medical care as our non-disabled peers.'

Ultimately Sam hopes that 'no one's life will be left to chance by medical or mental health professionals. I hope that one day we, and our lives, will be valued as much as those of people without disabilities.'

*** Name changed and some details removed to protect people's identities. Narrative based on a submission to the Royal Commission.**

Economic participation

The experiences of people with disability as they participate in the economy are as varied as the people themselves. Compared with similar countries, Australia has a poor record on the economic participation of people with disability. In 2010, 45 per cent of Australians with disability were living in poverty, while the average for countries in the Organisation for Economic Co-operation and Development (OECD) was 22 per cent.[300] In 2018, the median gross income for a person with disability of working age was $505 per week, less than half the $1016 median gross income of a person without disability.[301]

Socio-economic disadvantage

People with disability experience high levels of poverty and socio-economic disadvantage, and are more likely to experience financial hardship and unemployment, with lower incomes and higher costs associated with living with disability.[302]

Australia's income support system is highly targeted, with asset and means testing, detailed participation requirements and strict payment tapering.[303] Income support may be reduced or stopped as people secure employment or increase working hours. The *Willing to work* report found this can deter people from transitioning to employment.[304] One person with disability described the income support system as 'something of a two-edged sword, where a person's financial life is secured but at the expense of being sidelined and shunted into a cul-de-sac of neglect'.[305]

The report, *Shut out: The experience of people with disabilities and their families in Australia*, describes the socio-economic disadvantage of people with disability as systemic, and multi-dimensional.[306] Research notes that disadvantage is intergenerational,[307] and compounded by intersecting factors such as age, gender, cultural and linguistic background, sexuality, geographic location and First Nations status.[308]

We have also heard about the socio-economic impact of COVID-19 on people with disability. COVID-19 has presented a significant health and economic challenge globally and in Australia.[309] The Australian Government introduced two coronavirus supplement payments for eligible households and individuals to manage the economic impact of the pandemic.[310] We have heard about how the exclusion of people receiving the Disability Support Pension (DSP) from the supplement payments affected some people with disability.

One person described the impact of being excluded:

> It's neglect and discrimination against the disabled that the Government has excluded the disabled from the temporary corona virus supplement of $550 a fortnight for 6 months. The Government acknowledge there are additional costs due to the pandemic social distancing and lots of allied health services (especially community based services) being withdrawn or cancelled at the moment. Which means as a disabled man to stay safe and well during this pandemic I have

> to fund my health care out of pocket with private providers. I can't afford private health being on DSP and the pandemic has increased costs.[311]

Open employment

People with disability have told us about their experiences of violence and abuse in the workforce. One person said:

> I had never encountered before the level of staff-on-staff aggression that I did in this role. I had numerous negative interactions, but the one that will stand with me: 'Are you brain damaged?' This from a somewhat senior member of the public service.[312]

We have also heard about the consequences of people with disability being unable to participate in meaningful work on an equal basis.[313] Despite government investment in rehabilitation and employment-related services, the labour force participation rates for people with disability have remained largely unchanged for the past 20 years.[314] Some submissions have raised being unable to find work and experiencing discrimination in the workplace.[315] Another issue raised is the lack of opportunity for career progression. One employee with disability told us:

> I have been bullied, stereotyped, withheld from promotions, not ever asked to work up or fulfil my mangers role, despite being the most qualified, experienced & skilled person on the team, because I have a disability.[316]

Reasonable adjustments in the context of workplace include adjustments to employment conditions that allow people with disability to work safely and productively. But 'reasonable' adjustments can produce unintended consequences. One person said, 'there needs to be some formalisation of reasonable adjustments to the workplace to ensure … the worker is empowered … not humiliated or disempowered'.[317]

Article 27 of the *CRPD* requires the Australian Government as a State Party to take steps to employ people with disability in the public sector.[318] The Australian Public Service (APS) has developed a Disability Employment Strategy, which aims to increase the participation rates of people with disability and improve their experiences in the public sector workforce.[319] Despite initiatives such as the RecruitAbility scheme and affirmative measures, there has been little increase in the participation rates of people with disability in the APS since 2015.[320]

In response to the *Employment issues paper*, one woman with disability described her 'first hand evidence of governments neglect and abuse of their ongoing commitment to increase the employment and retention of people with disability in the public sector'.[321] She outlined the barriers she had experienced in the provision of reasonable adjustments, lack of support and inclusion, and ignorance about disability in recruitment and in the workplace.[322]

Segregated employment

> Employment can be an important protective mechanism for people with disability. With employment comes more independence, choice, a higher standard of living, exposure to new life experiences, and increased support networks, confidence and self-worth. Sheltered workshops with below-award rates of pay are not likely to offer these benefits.[323]

Australian Disability Enterprises (ADEs) largely employ people with cognitive disability, particularly people with intellectual disability.[324] Employees may perform a variety of tasks, including packaging, garden landscaping, cleaning, laundry services and food services.[325]

We have heard about violence against and abuse of people with disability in some ADEs, including the sexual harassment and assault of women and men with disability.[326] A joint submission from WWILD Sexual Violence Prevention Association and the Community Living Association told us that:

> Sexual harassment by other services users in supported employment or other group settings was highlighted. Exacerbating this is the experience of not being supported by the service when they make allegations or complaints, meaning that the individual is forced to continue to work alongside the perpetrator.[327]

Another person with disability described being bullied in the ADE where he works and being held back from progressing in employment:

> I am employed in an ADE and could not achieve my employment goals because ADE management did not comply with the agreement regulation between the ADE and DSS [Department of Social Services] resulting in a loss of income and deprived of training.[328]

He states that despite making complaints to the service provider no appropriate action was taken to resolve the situation.[329]

> Don’t put 100 people in a supported workplace together, and give them meaningless work and no hope.[330]

ADEs provide supported employment assistance to approximately 20,000 people with disability across Australia, funded by the Department of Social Services (DSS).[331] From 1 July 2020, DSS block funding of ADEs ceased and NDIS participants have the opportunity to use their funding to support their employment goals in open or segregated workplaces. This has resulted in ADE places being uncapped, and could lead to greater numbers of people with disability being employed in segregated workplaces.[332]

Wage inequity

> Fred was paid $3.30 per hour after 40 years. From what I could understand, the highest wages paid were about $6 per hour.[333]

Under certain circumstances, an employer can pay an employee a percentage of the minimum rate for the work they are performing, based on assessment of their work capacity. This assessment can only be carried out by a qualified independent assessor.[334] The employer must register their intent to pay 'productivity-based wages' with the DSS and the employee must meet set criteria.[335] This Supported Wage System provides a wage 'floor' of approximately $2.50 an hour.[336] In one submission, the father of a person with disability told us:

> He was paid on what they deemed as his 'work capacity' which amounted to $15 - $20 dollars a day (minus his bus fares) for approximately 6 hours work. Within the year, we were never invited to a meeting to review his 'work capacity' and he gave up. He felt undervalued.

In segregated workplaces, the *Supported Employment Services Award 2010* regulates employment. Evidence submitted to the Fair Work Commission suggests the average hourly rate of pay for people working in ADEs in 2019 was $7.00, alongside income received from the DSP.[338] This evidence suggests that increases to pay are largely mitigated by the resulting tapering of the DSP payment.[339]

Australian governments have a large number of policies and programs related to economic participation and employment of people with disability. We are interested in how these work together and what changes, if any, need to be made, including to relevant legislation. We will also explore the relationship between poverty, unemployment and underemployment, and violence against, and abuse, neglect and exploitation of, people with disability. We will also examine the experiences of people with disability in segregated employment settings.

National Disability Insurance Scheme (NDIS)

Our terms of reference direct us to consider the quality and safety of services provided by the NDIS under the NDIS Quality and Safeguarding Framework.[340] The NDIS is a major reform of social policy in Australia, replacing nine diverse Australian, state and territory systems of funding for supports and services for people with disability.

Appendix D provides a brief overview of the NDIS, including the development of the NDIS. The purpose and main features of the NDIS are described, as is the role of the NDIS Quality and Safeguards Commission that is responsible for the quality and safeguarding of the NDIS.

While still in the early stages of implementation, the NDIS has been reviewed a number of times.[341] As noted earlier in this chapter, the Royal Commission has not yet held a public hearing to examine issues relating to the NDIS, including issues raised in submissions. The Royal Commission is considering ways it may build on the recommendations of those reviews where they relate to violence against, and abuse, neglect and exploitation of, people with disability.

Core goals of economic and social participation

People with disability are often socially isolated and economically excluded.[342] The objects of the NDIS are, among other things, to:[343]

- support the independence and social and economic participation of people with disability
- enable people with disability to exercise choice and control in the pursuit of their goals and the planning and delivery of their supports
- promote the provision of high quality and innovative supports that enable people with disability to maximise independent lifestyles and full inclusion in the community
- protect and prevent people with disability from experiencing harm arising from poor quality or unsafe supports or services provided under the scheme
- raise community awareness of the issues that affect the social and economic participation of people with disability, and facilitate greater community inclusion of people with disability.

The NDIS Quarterly Q3 report 2019–20 looked at outcome measurements for participants, one year after they entered the NDIS. It noted that:[344]

- 51 per cent of participants do not choose who supports them, which represents a 2 per cent increase on the baseline rate before NDIS participation
- 45 per cent of participants are involved in community and social activities, often in the form of day programs, which represents a 10 per cent increase on the baseline rate before NDIS participation
- 25 per cent of participants are in work, which represents a 1 per cent increase on the baseline rate before NDIS participation.

These statistics may overstate the participant outcomes. For example, the community participation measure does not distinguish between those activities that may occur only with other people with disability and those that may be more inclusive. Likewise the measure of employment participation includes part time work, supported employment and ADEs as well as open employment.

However, we have heard about frustration and dissatisfaction that many of the intended benefits of the NDIS are yet to be realised. For example, IMPACT Community Services told the Royal Commission that front line staff have provided feedback that the NDIS can be difficult to access and navigate, and that there is significant confusion about whether NDIS providers are able to continue to support a person with disability when they are in the care of a health service.[345]

People with Disability Australia also told us:

> Despite the promise of the transformative power of the NDIS, group homes continue to offer little to no choice to people with disability regarding where they live and with whom they live. These fundamental rights to choice are denied, with decision-making largely made by providers and dependent on the availability of vacancies.[346]

Eric*

Eric has vision impairment and has been working for an Australia Disability Enterprise (ADE). In his submission he told us that the ADE has prevented him from achieving his employment goals and that he has been bullied there:

> The implementation of NDIS has not made any benefit for supported workers working for an ADE. Here again rules are not followed and there is a lack of transparency of how funding is spent.

Eric told us there are people working for ADEs who have suffered substantial income loss because of incorrect application of the Business Services Wage Assessment Tool.

Furthermore, he said, the Disability Maintenance Instrument used by the NDIS and disability service providers doesn't actually reflect individual needs: 'It is just a way for the service provider to increase income without giving much back to participants.'

Eric said the management team at his ADE didn't comply with their agreement with the Department of Social Services, causing him to lose income and training opportunities.

Eric told us he has reported this issue through various avenues but doesn't believe that appropriate action has been taken.

*** Name changed and some details removed to protect people's identities. Narrative based on a submission to the Royal Commission.**

Justice

People with disability, including people with mental illness and intellectual disability, are over-represented in the justice system.[347] The 2019 *Justice Project* report by the Law Council of Australia states that people with disability 'have high levels of interaction with the criminal justice system, both as victims and offenders', and that women with disability are especially 'vulnerable to crime and abuse'.[348] A 2018 report by Human Rights Watch indicated that almost half of all people entering prison have a disability, particularly cognitive or psychosocial disabilities.[349]

We have heard that people with disability face a range of systemic and practical barriers to accessing the justice system, including:

- lack of awareness of legal rights[350]
- lack of awareness and understanding of disability by people working within the system, including a failure to recognise disability[351]
- physical inaccessibility[352]
- lack of accessible information[353]
- lack of culturally appropriate supports[354]
- the nature of processes within the justice system, including inflexible court procedures.[355]

We have also been told that people with disability face difficulties in accessing legal assistance or advice,[356] and that non-legal supports and services including specialist disability and community supports, advocacy, health services, and accommodation support are important for people with disability engaging with the justice system.[357]

We are aware that people with disability have differing experiences of the justice system, influenced by the nature of their disability, their race, cultural identity, language, gender, sexual orientation and socio-economic background. We have been told that First Nations people with disability, in particular, face multiple forms of disadvantage and exclusion, which may further limit their access to justice.[358]

Submissions and research indicate that people with disability come into contact with the justice system at multiple points throughout their lives.[359] There appears to be a range of reasons for this, including:

- disadvantage, specifically disproportionately high levels of socioeconomic disadvantage, homelessness and poor health[360]
- the practices of people within the justice system, including the way in which police, lawyers, courts and others interact with, respond to and support people with disability.[361]

Criminal justice

People with disability may come into contact with the criminal justice system in a variety of ways. These include as a victim of crime, as a person accused of committing an offence, or as a person assisting law enforcement agencies, for example as a witness.

Police responses

We have been told about a range of experiences that people with disability have had with police. For example, we have heard people with disability have been disbelieved when they try to report abuse, including sexual violence, or have been treated as the offender, rather than the complainant.[362] Some organisations who have responded to our *Criminal justice system issues paper* have told us about concerns regarding police approaching or questioning people with disability and not identifying that the person has disability or making appropriate adjustments to the way in which they interact or communicate.[363]

We have also been told of the importance of increasing the availability of appropriate community supports or specialist workers as the first point of contact for people with disability, rather than relying on police.[364] Some responses to our *Criminal justice system issues paper* have argued the importance of increasing police training and awareness of disability, including improving their communication with people with disability, recognising 'invisible' disability and disability-related behaviours, and responding appropriately.[365]

Cycling in and out of the criminal justice system

Research by Professor Eileen Baldry indicates people with cognitive and psychosocial disability are at risk of being 'enmeshed' in the criminal justice system, caught in a cycle of short-term prison sentences without support in the community and at risk of becoming institutionalised.[366] We have heard that diversion programs and independent support people are important ways in which this cycle can be broken.[367]

Indefinite detention

'Indefinite detention' is when a person is held in custody under an order with an unspecified term.[368] This sometimes occurs when a person is charged with a crime and found 'unfit' to plead, or not guilty by reason of mental impairment (or equivalent), or is ordered to serve a prison sentence that does not have a fixed end date.

We have heard that people with cognitive or psychosocial disability are overrepresented in the number of indefinite detention orders, and in the length of time served in detention under those orders. For example, we have received submissions stating that in many jurisdictions a person with disability is at risk of being held in a prison or hospital for an indefinite period or a longer period than if they had been convicted.[369]

We have been told that indefinite detention and cycling in and out of the justice system is linked to inadequate supports and accommodation for people with complex needs outside of a custodial setting.[370]

Prisons and closed environments

We have heard that people with disability are at heightened risk of violence, abuse, neglect and exploitation in closed environments. The term 'closed environments' refers to facilities or places that may deprive people of their liberty by restricting their ability to leave and limiting those who can enter and access the environments. These include prisons and detention centres, forensic disability facilities, secure mental health facilities and some accommodation settings.[371]

We have received submissions that have raised concerns that some people with disability do not receive the basic assistance needed to maintain their health and safety in closed environments. People have described underlying medical conditions being untreated, prisoners with hearing impairments being unable to communicate, people being forced to barter food and belongings in exchange for assistance, and people being sexually assaulted by prisoners assigned as their 'carers'.[372]

We have also been told about prison or hospital staff using restrictive practices and inappropriate discipline on people with cognitive disability because they do not recognise or know how to address disability-related behaviours.[373] The use of solitary confinement to 'manage' people with disability has been raised by some as an issue of particular concern.[374]

Guardianship and administration

Guardianship and administration orders authorise a person to make decisions on another person's behalf.[375] Guardianship orders may cover decisions about a range of personal matters, including where a person lives, services, health care and other day-to-day matters. Administration or financial management orders authorise decisions about financial matters only.[376]

We have been told how guardianship and administration processes and orders can limit people's choice and control, and that this may be linked to violence, abuse, neglect and exploitation.[377] Some submissions described how people who are the subject of guardianship proceedings are not given the opportunity to participate or be heard in those proceedings.[378] Research conducted by the Australian Guardianship and Administration Council indicates that less than 50 per cent of people subject to guardianship or administration orders participate in their own case management, applications and review hearings.[379]

A number of submissions described the effect of limitations on choice and control under guardianship and administration orders.[380] For example, one person told us that guardianship:

> disenfranchis[es] the subject of an order and often results in the individual subject to lose self-confidence and tends to gradually erode their potential for independent thought – due to their having no other option but to submit to the regime involuntarily imposed upon them.[381]

People have also told us about neglect, abuse and financial exploitation occurring where guardianship and administration orders are in place.[382] For example, in one submission, we were told about a person with disability being verbally abused, isolated, and prevented from attending medical appointments by her guardian.[383] A number of submissions have described financial exploitation occurring under administration orders until they were brought to the attention of the Public Trustee.[384]

Guardianship and administration regimes have been the subject of previous inquiries and reviews.[385] The 2019 Victorian Ombudsman Investigation into State Trustees drew links between decisions under guardianship or administration orders and violence, abuse, neglect or exploitation. It identified numerous cases, including instances where State Trustees appointed as administrators had failed to manage their clients' finances, reduced a client's quality of life by placing them on restricted budgets, and neglected to consult clients on their wishes for their finances.[386]

Some information from Public Guardians suggests formal decision-making arrangements, such as guardianship orders, may be put in place in response to violence, abuse, neglect or exploitation.[387] We have also received submissions that have suggested formal decision-making arrangements may prevent violence, such as forced medical treatment.[388]

The Royal Commission will examine how violence, abuse, neglect and exploitation may be linked to guardianship and administration, including where they may be a source of protection. We understand these systems disproportionately affect people with disability and can have significant impacts on the lives of those subject to them. We will consider the extent to which the recommendations for National Decision-Making Principles made by the Australian Law Reform Commission have been implemented. We will also examine the operation and impacts of other formal decision-making arrangements in our work.

COVID-19

The COVID-19 pandemic has been an unprecedented public health, social and economic emergency. The *CRPD* outlines the rights of people with disability to health without discrimination on the basis of disability, including access to population-based public health programs and during situations of risk.[389] We have heard from people with disability and their representative organisations about people with disability who are, like many in the broader community, experiencing increased levels of anxiety about the COVID-19 pandemic and are also feeling they are not being included in government responses.[390]

A public hearing on the 'Experiences of people with disability during the ongoing COVID-19 Pandemic as at August 2020' is planned for August 2020. We will continue to examine whether Australian governments were inclusive of, and responsive to, the needs of people with disability during the COVID-19 pandemic as part of a larger focus on emergency planning and responses. We want to understand the experiences of people with disability in particular settings, such as group homes, schools and health systems, during emergencies and whether they are at higher risk of violence, abuse, neglect and exploitation at these times. This will be an aspect of our ongoing work, including public hearings.

Conclusion

The information and evidence we have received so far shows that many people with disability experience violence, abuse, neglect and exploitation across many different areas of their lives. These experiences are exacerbated for some groups, including First Nations people with disability and culturally and linguistically diverse people with disability.

People with disability have told us about violence, abuse, neglect and exploitation across a wide range of settings and contexts, including education, homes and living, relationships, health, community participation, economic participation and the justice system. We have started to hear about people's experiences with the NDIS. We have also heard about how people with disability have been affected by the COVID-19 pandemic.

A number of themes are emerging across these settings and contexts that are related to violence against, and abuse, neglect and exploitation of, people with disability. They include people's ability to exercise choice and control across all aspects of their lives and attitudes towards disability. We have also heard about the ways in which people with disability can be segregated and excluded from the wider community, and how restrictive practices are used across different settings.

Families, supporters and the workforce have been identified as having the potential to act as both a positive and negative force in the lives of people with disability.

We have also heard about challenges with oversight and complaint mechanisms, and how this may increase the risk of violence, abuse, neglect and exploitation, and may inhibit reporting and lead to poor responses.

We have heard about a lack of data on violence against, and abuse, neglect and exploitation of, people with disability. We have also heard about challenges around funding and the way that existing funds are targeted or distributed.

Over the course of our inquiry, we will continue to investigate the factors that increase the risk of violence, abuse, neglect and exploitation experienced by people with disability across a range of settings and contexts. We will also examine the preventative factors that decrease risk and take us towards a more inclusive society that supports the independence of people with disability and their right to live free from violence, abuse, neglect and exploitation. Our future work is described in Chapter 19, 'Our future direction'.

Endnotes

1 *Letters Patent* (Cth), 4 April 2019 amended 13 September 2019, (a).

2 *Letters Patent* (Cth), 4 April 2019 amended 13 September 2019.

3 *Convention on the Rights of Persons with Disabilities*, opened for signature 30 March 2007, 999 UNTS 3 (entered into force 3 May 2008).

4 *Letters Patent* (Cth), 4 April 2019 amended 13 September 2019, (g).

5 Australian Institute of Family Studies, *Enhancing family and relationship service accessibility and delivery to culturally and linguistically diverse families in Australia*, AFRC Issues No. 3, June 2008, p 3.

6 Australian Institute of Family Studies, *Enhancing family and relationship service accessibility and delivery to culturally and linguistically diverse families in Australia*, AFRC Issues No. 3, June 2008, p 4.

7 Australian Bureau of Statistics, *Disability, Ageing and Carers, Australia: Summary of Findings, 2018,* Catalogue number 4430, 24 October 2019. Results accessed using Australian Bureau of Statistics TableBuilder Disability status by Whether has a disability and Country of birth (broad groupings) and Main language spoken at home (broad groupings) and Proficiency in spoken English.

8 Australian Bureau of Statistics, *Disability, Ageing and Carers, Australia: Summary of Findings, 2018,* Catalogue number 4430, 24 October 2019. Results accessed using Australian Bureau of Statistics TableBuilder Disability status by Whether has a disability and Main language spoken at home.

9 Federation of Ethnic Communities, *New and emerging communities in Australia: Enhancing capacity for advocacy*, Report produced with funding from the Australian Government Department of Home Affairs, 2019, p 3.

10 Transcript, Jane Rosengrave, Public hearing 3, 2 December 2019, P-64 [32–33], P-65 [1–13]; Exhibit 3-20, Statement of Jane Rosengrave, 28 November 2019, at [28].

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18. First Nations people with disability

Key points

- There is no comparable word for ‘disability’ in the traditional languages of First Nations peoples.
- For cultural and historical reasons, many First Nations people with disability do not identify as being disabled or as a person with disability.
- Disability as it affects First Nations peoples has not been a prominent area of public policy discussion.
- First Nations people with disability often experience multiple forms of disadvantage.
- More than one-third of First Nations people have disability, which is considerably higher than in the non-Indigenous population.
- Available data suggests that 6 per cent of First Nations people with disability experienced physical violence in the previous 12 months.
- First Nations people with disability have shared their experiences of violence, abuse, neglect and exploitation with the Royal Commission.
- We have heard about First Nations people with disability being bullied or abused by people in positions of power, being subjected to restrictive practices, receiving inadequate care and being forced to socially isolate from the general population.
- The experiences we have heard about so far have been predominantly in education, justice, health care and accommodation settings.
- Between March and August 2020, the Royal Commission had to postpone planned public hearings, including a specific hearing focusing on the experiences of First Nations people with disability, due to the COVID-19 pandemic. In July 2020, the Royal Commission announced resumption of public hearings, including a specific First Nations hearing in November 2020, subject to any significant changes in circumstances.
- During COVID-19 and despite the postponement of face-to-face engagements, we have continued to engage with First Nations people and organisations online, including by video conference.

Content warning

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

Introduction

Australia's First Nations peoples comprise Aboriginal people of the mainland, Tasmania and other islands off the continent, as well as Torres Strait Islander people. One of the world's oldest living cultures, Australia's First Nations peoples make up just over 3 per cent of the nation's population, spanning 500 distinct cultural groups and speaking at least 150 different languages.[1]

Although there are cultural differences among First Nations peoples, there are also many similarities, such as caring for Country, traditional ceremonies, oral traditions and family responsibilities. These traditions have continued from the time of their ancestors and include caring for and providing support to First Nations people with disability.

While disability may be a new conversation in some First Nations communities, part of this story can be traced back 20,000 years to the footprint of a one-legged Aboriginal man hunting near Lake Mungo in New South Wales. Archaeological evidence from the site shows that the man had a pointed walking aid to help him participate in a group hunt, which was travelling at high speed.[2]

First Nations people with disability are specified in the Royal Commission's terms of reference as an area of focus.[3] As such, we aim to ensure that the voices of First Nations people with disability are at the forefront of our work. This chapter provides the context for understanding disability from a First Nations' perspective, including the data, policy and human rights frameworks on this issue. It will then outline what the Royal Commission has heard to date about violence against, and abuse, neglect and exploitation of, First Nations people with disability.

The emerging picture is that First Nations people with disability experience various forms of harm across many settings and face many barriers to their safety, wellbeing and inclusion in Australian society. This chapter outlines what we have heard so far about what it means to live as a First Nations person with disability in Australia and foreshadows the future work of the Royal Commission in this area.

Concept of disability in First Nations communities

> 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' ... 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.[4]

Disability is not a concept that readily translates into First Nations languages or cultures. However, there are words in traditional languages that describe what people see, and these words describe different types of disabilities. For example, in the Pitjantjatjara language from Central Australia, the word *nyumpu* means limping, but it can also be used to refer to anyone with general mobility conditions. *Kuru tjara* refers to someone who is blind or has sight issues, *pina tjara* refers to someone who is deaf or has hearing issues and *kulintja pulka* refers to someone with mental health issues.[5]

Many individuals with disability from First Nations backgrounds – and First Nations parents of children with disability – do not identify themselves or their children as a person with disability. For parents of First Nations children with disability, this reluctance may reflect their own experiences of stigma and shame, gaps in their knowledge, the inaccessibility of current systems, and other issues or events connected to the disability.[6]

The First People Disability Network of Australia (FPDN) suggests that the 'double discrimination' that First Nations people may experience due to their Indigenous status and their disability is important in understanding their experiences.[7] The concept includes the ongoing impact of colonisation, intergenerational trauma and the barriers First Nations people may face as they interact with various systems such as education, justice and health.[8]

We have been told that these factors can further marginalise First Nations people with disability and place them at increased risk of neglect at individual and systemic levels.[9] This can affect how First Nations people come to understand disability and whether they identify as having a disability in the first place. For First Nations people, disability may be seen as another issue to manage on the spectrum of disadvantage and may therefore not receive the attention that it needs.[10]

The impact of colonisation and the Stolen Generations have been raised as factors that might prevent First Nations people with disability accessing services.[11] Disability advocate the late Gayle Rankine identified the fear of child removal and subsequent institutionalisation as a particular barrier to First Nations people with disability accessing services.[12]

Despite these barriers, research indicates that First Nations people with disability participate in the cultural life of communities at equal rates with First Nations people without disability.[13] First Nations people with disability are often described within their communities by reference to where they are from and their functionality or uniqueness, rather than identified as less-abled than another person.[14]

These perspectives are closely linked to First Nations peoples' understanding of health and wellbeing, which is holistic and extends beyond merely an absence of physical pain or sickness to encompass physical, mental, cultural and spiritual health as important to overall wellbeing.[15] First Nations people with disability are seen for what they are capable of doing, as opposed to what they are not.

Discussions around disability are largely articulated in a way that is sensitive and respectful, rather than through labels or diagnoses.[16] Examples could include, 'Uncle doesn't hear too well' or 'cousin doesn't move around too well'.[17]

What the data tells us

By any measure, Aboriginal and Torres Strait Islander people with disability are among the most disadvantaged members of the Australian community. They often face multiple barriers to meaningful participation in their own communities as well as the wider community, facing double disadvantage because of discrimination on the basis of their Aboriginality as well as their disability.[18]

Data recently updated by the Australian Bureau of Statistics shows that more than one-third of all First Nations peoples (38 per cent) have disability.[19] The data shows that more than one in five First Nations children have disability (22 per cent) and almost half of all First Nations adults (48 per cent), aged 18 years and over, have disability.[20]

Around 31 per cent of First Nations adults have a physical disability, more than 20 per cent have a sensory disability and 11 per cent have psychosocial disabilities.[21] For First Nations children, sensory disability is the most common disability recorded (nearly 12 per cent), followed by cognitive disability (9 per cent), physical disability (5 per cent), and psychosocial disability (4 per cent).[22]

Organisations such as the FPDN suggest that these figures may under-represent the number of people with disability in First Nations communities once under-reporting, lack of awareness of disability and the impact of geographical factors on data collection are taken into account.[23] The limitations of the data to accurately describe the experiences of disability among First Nations people are widely acknowledged in the literature and among First Nations peoples.[24]

It is in this context that the Royal Commission is particularly interested in the circumstances whereby First Nations people may acquire disability and which may contribute to the high number of First Nations people with disability. As an example, the Royal Commission is aware that First Nations women were 34 times more likely to be hospitalised as a result of family violence in 2016–17 than non-Indigenous women, and is mindful about the potential ongoing effects of secondary causes of disability in these situations.[25]

Chapter 15, 'Nature and extent of violence against, and abuse, neglect and exploitation of, people with disability', outlines what publicly available data tells us about the number of people with disability in Australia and their experiences of violence, abuse, neglect and exploitation.

Available data suggests that First Nations adults with disability experience high rates of violence, with around 6 per cent experiencing physical violence in the previous 12 months.[26] This data represents the position at a particular point in time as opposed to the experiences of violence over a lifetime. Critically, there is no available data on violence against, and abuse, neglect and exploitation of, First Nations children with disability.

Despite these limitations, what is known about the experiences of First Nations people with disability suggests they are at higher risk of experiencing harm than the general population.

For example, they are:

- more likely to have experienced threats of physical violence[27]
- far more likely to have been removed and/or had relatives removed from their family[28]
- more likely to have experienced high or very high levels of psychological distress[29]
- more likely to be detained due to behaviours associated with a cognitive disability, fetal alcohol syndrome or other disability.[30]

While this provides important information on the circumstances of First Nations people with disability, addressing the data gaps is a key issue for the Royal Commission.[31] Alongside the views of First Nations people with disability, which we will explore throughout our inquiry, better data will provide a clearer picture on ways to address disproportionate disadvantage and support First Nations people with disability to live happy, healthy and safer lives.[32]

A human rights-based approach to disability for First Nations peoples

To achieve the Royal Commission's commitment to applying a human rights-based approach, our work needs to be informed by human rights standards relevant to First Nations peoples as a distinct cultural group, as well as their rights as people with disability.

The international instruments of particular relevance to the rights of First Nations people with disability in the context of this inquiry are the United Nations *Convention on the Rights of Persons with Disabilities* (*CRPD*),[33] the *Convention on the Rights of the Child*[34] and the *International Convention on the Elimination of All Forms of Racial Discrimination*,[35] all of which Australia has ratified. The Royal Commission will also be guided by the *United Nations Declaration on the Rights of Indigenous Peoples* (UNDRIP),[36] which Australia formally endorsed in 2009.[37] Collectively, these instruments provide a framework for examining the human rights of First Nations people with disability.

The *UNDRIP* represents a collective effort by First Nations peoples to develop a set of minimum rights standards for Indigenous peoples worldwide.[38] Articles 21 and 22 emphasise the importance of upholding the rights of First Nations people with disability, including taking steps in conjunction with Indigenous peoples to improve their economic and social conditions and their right to be free from violence.[39]

The Australian Human Rights Commission has articulated four key principles arising from rights contained in the *UNDRIP*, all of which are important for First Nations people with disability. They are:[40]

- safety and dignity
- self-determination
- respect for and protection of culture
- equality and non-discrimination.

Self-determination is a core component of the collective rights of First Nations peoples globally. For example, the First Nations community-controlled sector is a realisation of First Nations people expressing and implementing self-determination.[41] Unlike individual rights, such as the freedom to exercise autonomy, self-determination recognises the rights of First Nations peoples to have a say over matters that affect them through their own representatives, in a way that existed before colonisation.[42]

Academic literature emphasises that self-determination is the key to addressing disadvantage, maintaining culture and promoting wellbeing.[43] This right was also at the centre of the Uluru Statement from the Heart (Uluru Statement), which says: ‘When we have power over our destiny, our children will flourish.’[44] The Uluru Statement calls for the structural reforms that are needed for First Nations people to achieve self-determination, such as a First Nations Voice to Parliament enshrined in the Constitution, a process of truth-telling and a Makarrata Commission to facilitate agreement-making.[45]

The precise structural reforms proposed in the Uluru Statement are outside the Royal Commission’s terms of reference. Nonetheless, a submission to the Royal Commission emphasised that self-determination is critical to addressing the issues raised by the terms of reference.[46] That is because First Nations people with disability must have a say in matters that affect them, including the supports they need.[47] This is consistent with what we have heard so far from First Nations people, their representative organisations and other agencies, through our workshops, submissions and issues paper responses.[48]

Acknowledging the silence

> It is the unwritten chapter in our history of Australia and also in the First Nations rights movement history. We don’t have that chapter written … We know it must be written and this is an opportunity for First Nations peoples to have their voice, and voice their truth about what has been happening today … and in the past in relation to how First Nations peoples with disability are experiencing really serious levels of abuse, neglect and exploitation and violence.[49]
>
> Andrea Mason OAM, Ngaanyatjarra and
> Karonie woman and Commissioner

Despite the National Disability Strategy 2010–2020 (NDS) and the accompanying Australian Government Plan to Improve Outcomes for Aboriginal and Torres Strait Islander People with Disability (AGOP),[50] disability does not feature prominently in the broader First Nations policy arena.

First Nations disability advocate the late Uncle Lester Bostock OAM reflected on this issue in 2007, noting the need for a whole-of-government approach to disability and for it to be included in the broader Aboriginal rights movement.[51] Citing the outcomes of extensive consultations, he identified that ‘Aboriginal people frequently voiced frustration at having to compete with a range of other issues’ that confront their communities and that disability was often ‘overshadowed’[52] by other priorities.

A 2015 Australian Human Rights Commission report, *Aboriginal and Torres Strait Islander social justice and native title report*, emphasised a need to elevate disability in the policy discussions concerning First Nations peoples.[53] The report noted that disability had been long overlooked, further marginalising First Nations people with disability and ignoring their distinct needs.[54] This was followed by a call from a coalition of First Nations peak organisations in the Redfern Statement for the Australian Government to do more to meet the needs of First Nations people with disability.[55]

The *Closing the Gap report 2020* does not specify disability as a priority area,[56] despite persistent calls to include it.[57] Disability does not sit alongside the existing indicators in the framework as a standalone target monitoring child mortality, early childhood education, school attendance, literacy and numeracy, Year 12 attainment, employment and life expectancy.[58]

The FPDN maintains that disability is not just a ‘health’ issue within the Closing the Gap framework, but one that is relevant to other areas such as children and families, justice and housing.[59] As Dr Scott Avery has said in relation to this issue, disability has largely been excluded from ‘the book of Australian Indigenous policies such as Closing the Gap’.[60] The new Closing the Gap National Agreement (National Agreement), which was announced at the end of July this year,[61] presented an opportunity to elevate the rights of First Nations people with disability.

The Royal Commission welcomes the shared responsibility across all governments under the National Agreement, including the references to disability status and the importance of data across some of the 16 new target areas.[62] However, the Royal Commission notes that the changes have not included a stand-alone target on disability and that this has been lamented by FPDN.[63]

Australia has committed to implementing the *CRPD* for the betterment of all people with disability. The long awaited inclusion of disability in the Closing the Gap Framework under the new National Agreement may be considered by some as taking a staged approach to elevating disability as a key area of concern and investment. The strategy focuses on building up First Nations disability services and advocacy providers and improving the capture of data on people with disability by targeting some key areas aimed at improving outcomes.

It is welcome news that the National Agreement is being presented as a living document, open to change as new information and considerations come to light. In regards to this, the work of the Royal Commission will be a source of information to enlighten and enliven discussion regarding content on disability in the National Agreement.

Disability an unwritten chapter

For many First Nations people, the issue of 'disability' represents the 'unwritten chapter' in the national policy and rights framework.

This omission from public policy also throws a veil over the discussion of disability in First Nations communities. For some, the abuse of people with disability is an 'open secret', occurring in plain sight and a source of community discussion and concern.[64] For others, 'the abuse happens behind closed doors, away from the transparency and accountability of community, family and culture'.[65]

The role of this Royal Commission is to shine a light on these individual and systemic experiences of violence, abuse, neglect and exploitation. In doing so, the Royal Commission wants to emphasise that we are here to provide a safe place for all First Nations peoples to share their truth.[66] By seeking to centre the voices of First Nations people with disability through our work, the Royal Commission is asking First Nations people to help us share their experiences. We acknowledge the fatigue that First Nations people may feel about the revolving door of reports and inquiries that have concerned them over many decades.[67] However, the Royal Commission is committed to identifying opportunities to support First Nations people with disability to live fuller, safer, more inclusive lives.

Supporting a First Nations disability sector

The Royal Commission acknowledges the work of the FPDN as the First Nations peak body for disability as well as the work of the various state and territory bodies and First Nations community-controlled organisations.

Collectively, these groups represent the primary points of culturally appropriate contact, services and support for First Nations people with disability. However, the demand for such support and the lack of a comprehensive national approach has led some organisations including FPDN to emphasise the need to progress the development of a First Nations disability sector.[68]

The Royal Commission acknowledges this call and seeks to better understand what such a sector would look like and how it would operate alongside other existing frameworks, systems and services.[69]

In contrast to the health services sector, there is no First Nations community-controlled disability sector. The reasons for this could be that disability is a newer conversation among some First Nations people and is not a prominent national policy priority.[70] First Nations disability advocate and scholar Dr Scott Avery has said of this disparity, ‘It must be remembered that in many ways the social movement of Aboriginal and Torres Strait Islander people with disabilities is starting from an absolute baseline position.’[71]

Experiences of First Nations people with disability

The Royal Commission has heard accounts of First Nations people with disability experiencing violence, abuse, neglect and exploitation across many different settings. In some ways, these experiences are distinct from those of non-Indigenous people with disability, as for some people they can affect their ability to express and practise their culture as well as their health and wellbeing.

First Nations people with disability have told us that their experiences are often compounded by barriers such as multi-layered disadvantage associated with colonisation, poverty, chronic health conditions, racism, intergenerational trauma and a lack of culturally appropriate services.[72]

This section outlines what First Nations people have told us so far about these barriers and how they are affecting their experiences of violence, abuse, neglect and exploitation.

Colonisation and intergenerational trauma

Information shared with the Royal Commission has emphasised the ongoing impact of colonisation on the lives of First Nations people with disability,[73] including health outcomes, disadvantage and intergenerational trauma, and the need for greater self-determination in First Nations communities.[74]

The Queensland Aboriginal and Islander Health Council (QAIHC) made a submission to the Royal Commission outlining the ongoing impact of historical policies on the lives of First Nations people. QAIHC maintained that it was ‘particularly damaging’ to assume that ‘past injustices have been resolved and are non-consequential for health policy’.[75]

The National Health Leadership Forum (NHLF) also identified the role played by the colonial legacy of systemic abuse and dispossession in the development of complex intergenerational trauma.[76] NHLF argued that First Nations peoples do not have an equal opportunity to be as healthy as other Australians because of the ongoing impact of past injustices on their experiences of abuse and neglect.[77]

Similarly, a joint project by the Healing Foundation and the Australian Institute of Health and Welfare used a statistical technique to estimate the number of people with disability who were members of the Stolen Generations.[78] The available data indicated that about two-thirds of Stolen Generations survivors were living with disability or a restrictive long-term health condition.[79] The project also identified poorer outcomes for Stolen Generations survivors compared to a reference group across a range of areas including but not limited to physical and mental health,[80] experiences of barriers when accessing services,[81] and a higher rate of homelessness.[82]

One First Nations person with disability who identifies as a member of the Stolen Generations told us about the impact the policies of forcible removal have had on his life. This included being removed from his parents at a young age after needing surgery, with his parents then deemed as not having the capacity to look after him.[83] He said he grew up in babies' homes and foster care, which kept him far away from his family and culture and the life that he 'should have been living.'[84]

Institutional racism

First Nations people with disability have also brought to our attention the role of racism, and particularly institutionalised racism, as part of their experiences of violence, abuse, neglect and exploitation.[85]

The Lowitja Institute and Just Reinvest NSW expressed concern about indirect institutional or systemic biases that First Nations people with disability experience when accessing services, housing and employment and exercising their rights.[86] Likewise, the Queensland Human Rights Commission emphasised the 'layer of hardship' that racism adds for First Nations people with disability, particularly in relation to their over-representation in the justice system, which in turn may increase their vulnerability to abuse.[87]

In its submission to the Royal Commission, QAIHC emphasised racism in health and hospital services in Queensland, citing a 2017 audit that revealed 10 of 16 services had 'extreme' levels of institutional racism, with the remaining six having 'very high' levels.[88] QAIHC discussed the need to address institutional racism in the health sector, including the role that various policies, structures, practices and perspectives can play in limiting the access to or quality of health care available to First Nations people with disability.[89]

The NHLF also emphasised the role of institutional racism in the lives of First Nations people with disability in its submission to the Royal Commission.[90] It raised concerns about the way in which major policy responses are framed and delivered; that is, based on Western norms that largely ignore the needs of First Nations peoples.[91]

Similarly, we have been told that the National Disability Insurance Scheme (NDIS) does not adequately cater for the needs of First Nations people with disability.[92] First Nations people have told the Royal Commission they find the NDIS difficult to navigate and understand and, when they do, it lacks the flexibility to support their cultural wellbeing.[93]

In their submission to us, the NHLF has maintained that the NDIS assessment process has ‘effectively reduced the number of people that will receive support’.[94] They have argued that at least 60,000 First Nations people are eligible for support through the NDIS.[95] Yet according to recent reports, only 22,749 First Nations people are receiving support.[96]

Poverty and socio-economic disadvantage

Australians with disability experience higher levels of poverty than those without disability.[97] Research indicates that poverty is particularly prominent among First Nations people with disability,[98] with submissions to the Royal Commission raising this as an issue which further exacerbates their experiences.[99]

Available data suggests that First Nations people with disability experience poverty to a greater extent across a range of indicators.[100] Information received from the Lowitja Institute and the NHLF has stressed that assessments of the health of a First Nations person with disability must also consider factors such as housing, poverty and cultural expression, which are critical to health outcomes.[101]

First Nations people with disability have told us that disability support often fails to cater for their basic daily needs, such as access to food, water and shelter.[102]

A range of other issues associated with poverty have also been raised with the Royal Commission, such as the disproportionate number of First Nations people with disability in the criminal justice system because of unpaid fines or the failure to register vehicles,[103] and on social welfare and income management.[104] The Royal Commission has been informed of the potential impact of forms of income management such as the BasicsCard and Cashless Debit Card on First Nations people with disability.[105] These include issues associated with greater social exclusion, food security and being humbugged or harassed for money.[106]

Poorer health

First Nations people have described to the Royal Commission the extent to which chronic health conditions, such as diabetes, renal failure and heart disease, lead to disability.[107] The higher prevalence of preventable diseases among First Nations peoples and the significant health disparities that persist between First Nations and non-Indigenous people have been identified by the Lowitja Institute as a consequence of systemic failures in the health care settings.[108]

We have heard that First Nations people with disability experience barriers to accessing comprehensive support for their health needs, particularly in justice settings.[109] In some cases, we have been told that First Nations people must travel or move away from social supports, Country and culture to access quality health services.[110]

Concerns have also been raised about the effect of limited access to quality health care, housing and infrastructure on the health and wellbeing of First Nations people with disability.[111] The expensive nature of travel, diagnoses and equipment may be out of reach, particularly in the context of poverty and cost-of-living challenges, when there may be a struggle to pay for essentials such as food, blankets and rent.[112]

Homelessness and barriers to accommodation

The Australian Bureau of Statistics reports that First Nations people with 'profound or severe' disability were almost twice as likely as First Nations people without disability to have experienced homelessness.[113]

First Nations people with disability have described the way in which poverty and geographical factors may affect their access to safe and appropriate housing.[114] We have also heard that those who live in regional and remote areas may need to travel vast distances to access basic necessities and that this places additional strain on First Nations people with disability.[115] In particular, this may compound already high costs of living and access to fuel, medicines, groceries and equipment.[116]

The Ngaanyatjarra Pitjantjatjara Yankunytjatjara Women's Council Aboriginal Corporation in particular emphasised the barriers facing First Nations people with disability who live in remote areas:

> A lot of these people out bush, they are coping with things we don't have to normally cope with – overcrowded housing, people coming and going, plumbing that doesn't work all the time; all of these things that make caring for anyone more of a challenge ...[117]

Housing availability has also been identified in research, in submissions and at our early workshops as contributing to the exposure of First Nations people to family violence[118] and as a barrier to those with disability gaining greater autonomy in their lives.[119]

Settings of violence, abuse, neglect and exploitation

First Nations people with disability have begun sharing their experiences of violence, abuse, neglect and exploitation with us. Based on what they have told us, we have learned that these experiences occur in a range of settings where individuals are being subjected to bullying or abuse by those in positions of power, restrictive practices, inadequate standards of care, and segregation from the general population.[120] We have also heard about domestic and family violence as a factor affecting the lives of First Nations people with disability and their families.[121]

This section explores what we have heard from First Nations people with disability about their experiences in various settings, such as family and community environments, education, health, justice and group homes or alternative accommodation. The information paints a disturbing picture of the experiences of First Nations people with disability and the complex and vulnerable situations they can encounter.

Relationships

First Nations communities have reported the extent to which violence occurs in their personal and community settings,[122] including in situations where foster children have been abused by their carers,[123] people with disability are being harmed by their carers or where women are harmed due to family violence.[124]

We have been told that these experiences are having significant consequences which may result in acquired brain injuries or disabilities.[125] Similarly, concerns have been raised with the Royal Commission about First Nations Elders with disability who may experience harm:

> The violence that's perpetrated, particularly against people with a disability – and we see our Elders every day that are being, you know, perpetrated violence against in their homes. They're getting their pensions taken off. They're … experiencing lots of abuse by their own family. And so those things are really big things.[126]

Through community engagements and workshops, First Nations people are sharing stories highlighting key issues, including how those with disability could be better supported to live safer lives, free from violence.[127] The message is that caring and cultural obligations are strong in First Nations communities and are a key consideration in providing support and responses to experiences of violence and abuse that may be occurring in this context.[128]

The Royal Commission has been told about the limited availability of culturally safe and trauma-informed services to help First Nations people with disability experiencing domestic and family violence.[129] First Nations people have also said they do not feel comfortable raising these matters with the police or child protection services.[130]

Education and learning

The Royal Commission has been told that First Nations children with disability are experiencing violence, abuse and neglect in educational settings, and that some teachers and schools are ill-equipped to cater for their needs.[131]

The use of restrictive practices, segregation, isolation and exclusion to manage behaviour has been raised as an area of concern for First Nations students with disability.[132] We have been told this has involved picking children up and moving them, or locking them in storerooms or separate rooms, away from other children.[133] In one case, we were told that a child was forcibly relocated by four teachers who each held one of the child's limbs and carried him screaming to a small room.[134] The child's father told us that this storage room consisted of a beanbag and a hole in the door to serve as a window and was used for long periods in an attempt to calm his son down.[135]

The Royal Commission has been told about instances where students have been socially isolated from their peers on school grounds, including during recess, lunch[136] and while others participated in sport or accessed the library,[137] and during extracurricular activities such as school excursions.[138]

A number of First Nations people have expressed concerns at the use of suspension and detention to manage the behaviour of children with disability.[139] One participant at a workshop hosted by the Royal Commission told us that children as young as three were being suspended for poor behavioural and emotional regulation but were not being assessed, diagnosed or getting the appropriate supports.[140]

One caregiver informed us the child in their care had been suspended 28 times in a single year,[141] while another parent told us her son was suspended for a total of 86 days in one school year.[142] This mother raised concerns that during her child's periods of suspension there was little information to support his learning or transition back to school.[143] Another parent told us that her son was suspended for 'silly things' such as making spit balls and not sitting still, often being singled out and segregated from his peers.[144]

One parent told us that she was worried about what she believed was a tendency of the school to 'blame' the child with disability.[145] She went on to tell us that her son was told that he needed to 'choose to concentrate on his work' and 'limit distractions'.[146] Another mother told us that her child would get frequent detentions for being 'unable to focus,' 'disorganisation', or being unable to complete tasks as the same rate as other children.[147]

First Nations people have also raised issues in relation to a lack of support for First Nations children with disability in the school environment. For one parent who wrote to us, the inability to secure individualised assistance for their son meant he was placed into 'mainstream' classes.[148] This parent told us that as a result their child did not get the help that he needed and was often left to ride a tricycle in the school yard or complete 'endless colouring in'.[149] Another person raised concerns about the disregard for the intelligence or ability to learn of a 15-year-old child, who she described was simply 'at school watching Disney movies'.[150]

Justice

A range of concerns have been raised with the Royal Commission about the experiences of First Nations people with disability in the criminal justice system. This includes concerns relating to treatment in custody, indefinite detention, racism and issues relating to diagnosis.[151]

Jesuit Social Services told us in its response to our *Criminal justice issues paper* that First Nations people with disability need a 'holistic, integrated and culturally responsive model of care' to help address high rates of incarceration.[152] First Nations people are grossly over-represented in the criminal justice system and in June 2019 comprised 28 per cent of Australia's prison population.[153] Likewise, in 2018–19, First Nations children and young people were 23 times more likely to be in detention than non-Indigenous young people.[154] This has profound implications for those who also have a disability, both diagnosed and undiagnosed.[155] The Royal Commission has heard that First Nations people often enter the criminal justice system with a diagnosed or undiagnosed disability[156] and, in the latter case, this entry may be the first time the disability is recognised or addressed.[157]

Submissions we have received have stated that available data indicates around 25 per cent of First Nations children and young people who are in custody in New South Wales have an intellectual disability,[158] and an estimated 87 per cent have symptoms consistent with a psychological disorder or signs of fetal alcohol spectrum disorder (FASD).[159] This is supported by a study in Western Australia that revealed high rates of FASD and neurodevelopment impairments among First Nations children in detention.[160]

In a submission in response to our *Criminal justice issues paper*, the Australian Human Rights Commission stated that First Nations children and young people with cognitive disabilities are more likely:

- to have their first interaction with police at a young age – around 13 years old[161]
- to be charged with an offence at a younger age than those of the same age without disability.[162]

Having been incarcerated, the available data suggests that the likelihood of a person with an intellectual disability returning to prison is more than twice the rate of someone without disability.[163] In its response to our *Criminal justice system issues paper*, the National Aboriginal and Torres Strait Islander Legal Services (NATSILS) described the intersection of racism, discrimination and disability as a type of 'quicksand', trapping First Nations young people in the criminal justice system.[164]

Human Rights Watch (HRW) indicated in its submission to the Royal Commission that some First Nations people have told them that they do not seek help for their disabilities while incarcerated because they are confronted with racist stereotypes, negative attitudes or lack of interest.[165] A First Nations prisoner interviewed by HRW said that correctional officers have been known to refer to First Nations people as 'pricks' and 'sheep', as well as derogatory names linked to skin colour, race and ethnicity.[166]

We have been told about a First Nations man who uses a wheelchair being left on the ground, unable to get up, for up to five hours after falling from their chair while showering inside a correctional centre.[167] We were also told about another First Nations person, who has spina bifida and renal failure, being stopped by a new member of the police force because the officer assumed that she was drunk.[168]

Indefinite detention has also been raised with the Royal Commission as an area of the criminal justice system requiring urgent attention, particularly for First Nations people with disability.[169] We have heard that there are a number of First Nations people with disability who are subject to long-term forensic orders and who may be spending longer in custody under these orders than they would if they had been found guilty of the offence.[170]

Health care

The Royal Commission has been told in workshops, submissions and public hearings[171] about the nature and extent of violence, abuse, neglect and exploitation in health settings. First Nations people with disability have raised issues involving racism and ableism,[172] health disparities,[173] neglect and the inability to access culturally safe and high-quality health care.[174]

We have heard in workshops and submissions that instead of seeing First Nations people with disability as human beings first, initial health responders have seen only race or disability.[175] For example, one person told us of being subjected to what he described as derogatory comments by paramedics. He said they assumed that the cause of his declining physical condition was intoxication, not disability.[176] The man told us he is a quadriplegic and his body had overheated, resulting in him needing to go to hospital and rendering him unable to communicate:

> … 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.[177]

The use of restrictive practices in the health care sector on First Nations people with disability has also been raised with the Royal Commission.[178] One mother told us about how her son was handcuffed for 24 days while in hospital and administered medications to sedate and control his behaviour.[179] Another First Nations woman described how her mother was placed on a behavioural management plan, which included taking away her phone and placing her at the end of corridors or closed rooms.[180] The daughter explained that these efforts were used in response to her mother crying out in pain and to prevent her from contacting family members and 'disturbing the rest of the ward'.[181]

She went on to tell us that:

> It is hard to call these settings anything other than prisons. They were places where she was confined and deprived of dignity and her liberty, they were places where physical, sexual and emotional abuse occurred. They resembled asylums.[182]

We have also heard that some hospitals have limited resources and inadequate staffing ratios to meet the needs of people with disability while in hospital.[183] One First Nations person explained that due to her mother's needs and the number of staff needed to bathe her properly her mother would often have to wait to be helped with her bath or only receive a bath in her bed.[184] She also told us her mother was sometimes left for hours before she was helped to have her meals.[185]

Organisations such as HRW and Sisters Inside have also told us that First Nations people with disability are not able to access adequate and immediate medical treatment and mental health support while incarcerated.[186]

Information shared with us has also highlighted First Nations people living in rural and remote areas do not have the same access to medical facilities or professionals as those who live in or closer to metropolitan areas.[187] Concerns have been raised that this can result in families needing to leave Country and travel long distances to access supports or going without appropriate help if they are not able to travel.[188]

Homes and living

For some First Nations people with disability, living at home with family is not possible. As a result, First Nations people with disability live in a range of residential options, such as group homes, hostels, residential care and disability-specific accommodation.[189]

The Royal Commission has heard that because no appropriate alternative accommodation is available, some First Nations people with disability live in settings such as locked or residential care facilities, hospitals, prisons, or aged care homes.[190]

Submissions that we have received from First Nations people about their experiences in these residential settings indicate that the quality of care varies greatly.[191] Concerns have been raised about difficulties associated with living away from Country,[192] the availability of accommodation providers,[193] and the quality and nature of care that some First Nations people with disability may be receiving.[194] A number of disturbing concerns have also been raised about the harm some First Nations people may be experiencing in these settings, including fears held by their family members for their safety, welfare and wellbeing.[195]

A parent described to the Royal Commission various incidents involving their child, who was living in a group home for a number of years.[196] This included concerns their child was forced to eat food covered in flies, and bathe in a communal bath that was not being cleaned properly and where faeces were circulating through the pipes.[197] The parent also said that her child was left unsupervised and able to harm himself, causing much distress to the family.[198]

First Nations people have shared other experiences such as being isolated in separate rooms,[199] during meal times[200] as well as missing meals,[201] or being fed meat when they were vegetarian.[202]

The Royal Commission has heard the deep distress of family members at the refusal of management, police and oversight bodies to acknowledge, respond to or address the concerns raised.[203] As one submission explained, ‘After none of these incidents of physical violence was there appropriate accountability or disciplinary action that took place.'[204]

Some staff were described as being rough and rude in their handling of First Nations people with disability, such as when they were being bathed; in some instances 'bruising' patients because they were in a rush due to the facility being understaffed.[205] One First Nations person attributed these experiences to insufficient workforce capacity, including a lack of training and skills.[206]

Areas for future consideration

The Royal Commission has heard from a variety of organisations and individuals from across the country about the varied experiences of First Nations people with disability as they relate to violence, abuse, neglect and exploitation.

The COVID-19 pandemic and subsequent public health response have temporarily prevented the Royal Commission from carrying out further face-to-face engagements with First Nations communities, and from conducting public hearings focusing on the experiences of First Nations people with disability. This has affected the scope and volume of information we have been able to include in this interim report, including the experiences of Torres Strait Islander people with disability, their families, carers, advocates and organisations. However, we have continued to engage by videoconference and phone with First Nations people with disability and their representative organisations. More information on this can be found in Chapter 9, 'Community engagement'.

This chapter has drawn on the information and experiences that have been shared with the Royal Commission so far, as we start to identify some of the issues affecting First Nations people with disability. We know that we have much more work to do to engage with First Nations people with disability so that we can tell a more complete story of their experiences of violence, abuse, neglect and exploitation and the issues that require action. Together, we need to identify solutions and chart a course for reform.

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Ralph*

Ralph is a First Nations man in his thirties. He is Deaf and has psychosocial disability. In his submission, he told us he has been abused, bullied, harassed and discriminated against all his life because of his disability:

> In life I had no support and all this experience impacted my depression and anxiety. I was a survivor of suicide, twice … all this trauma of life … and the missed opportunities of good education … good jobs and good future.

It began in foster care during the 1990s, when he was abused by his foster parents:

> They both hurt me. When I was [nine] and [10] my foster father tried to choke me and my foster mother tried to break my finger. They both hit me … It was so traumatic. I had to live it until I was out of care when I turned 18.
>
> At the time I didn't know any services or education on where to get help. I still live in pain from this.

The abuse continued at school, which Ralph describes in his submission as a 'difficult time'. In primary school the teachers would restrain him almost every day.

In high school, he recalled, the teachers told him he wouldn't be able to go to university to get a social work degree, because of his disabilities. He wasn't allowed to choose the subjects he wanted to study – those decisions were made by the teachers: 'I wasn't able to make subject decisions like other mainstream students … I went to TAFE and did a community service and business management course and completed it.'

Staying in paid employment has been challenging, Ralph told us. He has been harassed and bullied because of his disabilities, and employers don't want to know about his needs for reasonable adjustments to the work environment.

'I tried to advocate myself but the battle was difficult to win over,' he said:

> I worked at a coffee shop in [a] support[ed] employment program … they decided not to pay me full wages (70 per cent), which I didn't agree.
>
> The employer said it was because of my learning disability … The boss clapped in my face and yelled at me … and had no attention in learning about my disability. I had anxiety meltdown at this job.
>
> I brought in my psychologist to try and manage things but when my psychologist left my work

> the supervisor had a go at me, saying 'how dare you bring your psychologist in my workplace'. I had no choice but to resign.

Now things are a bit better for Ralph. He gets medical care, has regular appointments with a psychologist and has a disability support provider through which, he told us, he has learned 'many things about speaking up and human rights'.

Ralph gets involved at his place of employment and talks about disability human rights, organisation policy and practice.

'People with disabilities don't know how to speak up as they feel they are too controlled by carers,' he noted.

Ralph said he feels excluded from his culture, that Indigenous people with disability have a lot of trauma, and there's a real lack of understanding:

> There is not enough education or awareness out into the community. It feels like we are hopeless and people don't understand the life we live.
>
> We need to work on equality and [be more] inclusive in Australia ... We need more disability advocates like myself ... We also need politicians to listen to us.

*** Name changed and some details removed to protect people's identities. Narrative based on a submission to the Royal Commission.**

19. Our future direction

Key points

- The Royal Commission has made substantial progress in examining the issues set out in our terms of reference. But there is still much to do.
- We will continue to ensure that people are supported to share their experiences and expertise with us in the way that works best for them, whether through submissions, private sessions, community engagement activities or public hearings.
- All of the information and evidence that we receive will come together to inform the recommendations that the Royal Commission will make in our final report, due by 29 April 2022 according to the letters patent.[1]
- Our final report will present an evidence-based argument for change, with practical and implementable recommendations for reform that will seek to prevent and better protect people with disability from violence, abuse, neglect and exploitation.

Introduction

> What is happening to people is not okay
> and the stories need to be told.[2]

The Royal Commission has heard about violence, abuse, neglect and exploitation experienced by people with disability across a variety of settings and contexts in Australia. We have been told about a range of experiences that point to systemic and structural failures across multiple and overlapping systems.

We have made substantial progress in examining the issues set out in our terms of reference.[3] Many people and organisations have shared their experiences and expertise and have provided thoughtful and useful information during the first 15 months of our inquiry. However, there is still much to do.

This chapter sets out how we will build on our work to date and conduct the remainder of our inquiry.

What we will examine

The Royal Commission's task is broad and complex. Our terms of reference cover all forms of violence against, and abuse, neglect and exploitation of, people with disability in all settings and contexts in Australia, as detailed in Chapter 3, 'Our terms of reference'.

Our work to date, and in the future, will inform the recommendations that we make in our final report. The terms of reference state that the Royal Commission is required to deliver our final report and recommendations by 29 April 2022.[4]

As at 31 July 2020, the Royal Commission had held three public hearings. Chapters 12, 13 and 14 outline the themes that emerged from the evidence, along with areas where the Royal Commission will undertake further inquiry.

As detailed in Chapter 15, 'Nature and extent of violence against, and abuse, neglect and exploitation of, people with disability', the Royal Commission will examine how to improve the availability and quality of data on the violence, abuse, neglect and exploitation experienced by people with disability. We have noted that governments and organisations should not wait for the Royal Commission's final report and recommendations to begin addressing data gaps.

The Royal Commission intends to examine the themes and issues outlined in Chapter 17, 'Emerging themes and key issues'. We have heard about violence against, and abuse, neglect and exploitation of, people with disability across a wide range of settings and contexts, including education, homes and living arrangements, relationships, health, community participation, economic participation, and justice, including guardianship and administration arrangements. People have also started to share their experiences of the National Disability Insurance Scheme (NDIS). We have also heard about the experiences of people with disability during the COVID-19 pandemic and of government responses to that crisis. The Royal Commission will further investigate violence, abuse, neglect and exploitation in these settings and contexts to build our knowledge and inform our recommendations.

A number of themes have emerged that affect many or all aspects of the lives of people with disability. The Royal Commission will examine the ability of people with disability to exercise choice and control in all aspects of their lives, attitudes towards disability, and segregation and exclusion. We will also investigate the use of restrictive practices across a range of contexts, including education, homes and living arrangements, health and justice settings. The impacts of these practices will be explored as well as how their use can be avoided, prevented or minimised and, if they are required, what rules and safeguards should apply.

The relationship between the opportunities people with disability have to participate economically and violence against, and abuse, neglect and exploitation of, people with disability, will be considered in our future work. The Royal Commission will explore the experiences of people with disability in the workplace, including in open and segregated employment, such as Australian Disability Enterprises.

Through our work to date, the Royal Commission has heard how families, supporters, advocates and the workforce can support people with disability and facilitate their independence and autonomy. We have also heard how they can ignore or minimise violence, abuse, neglect and exploitation, or be a source of harm. Our further work will continue to examine the ways in which people in these roles may contribute to, or reduce the risk of, harm experienced by people with disability.

The Royal Commission will also investigate the provision and accessibility of services and supports across Australia, and how this affects the experiences of people with disability. This includes exploring how representation and advocacy may both help prevent and better respond to violence against, and abuse, neglect and exploitation of, people with disability.

People have described to us a number of challenges and limitations with existing oversight and complaints mechanisms, and that these may result in instances of harm being ignored, minimised or unreported. The Royal Commission will continue to investigate how failures in these systems may increase the risk of violence, abuse, neglect and exploitation for people with disability.

Over the course of our inquiry, the Royal Commission will further investigate the factors that increase and decrease the risk of violence, abuse, neglect and exploitation experienced by people with disability across a range of settings and contexts. This will include a focus on the way funds are targeted or distributed, and the ways that government policies may increase the risk of violence, abuse, neglect and exploitation.

In conducting our inquiry, we will look at the multi-layered experiences of people with disability and the particular experiences of culturally and linguistically diverse and First Nations people with disability.[5] In Chapter 18, 'First Nations people with disability', we outlined the experiences of First Nations people with disability, as well as the compounding nature of colonisation and intergenerational trauma, institutional racism, poverty and socio-economic disadvantage, poorer health and homelessness on their lives.

The Royal Commission may also identify other themes and issues as we gather further evidence and information, and consider what should be done to prevent, and better protect people with disability from, violence, abuse, neglect and exploitation in different settings and throughout their lives. The Royal Commission will examine what is needed to create a more inclusive society, where people with disability are accepted and valued, and where their independence and right to live free from violence, abuse, neglect and exploitation are upheld.[6]

We will build on the information and experiences shared with us to date and chart a course for reform. The Royal Commission is committed to identifying opportunities to support people with disability to live fuller, safer, more inclusive lives, now and in future.

How we will continue our work

We will continue to approach our work as outlined in Part B, ‘How we do our work’. At all times, our work is guided by our values and Accessibility and Inclusion Strategy (see Chapter 5 ‘Our organisation’).

> … the most important part of the Royal Commission’s work is our engagement with people with disability, their families and supporters. Your contributions will be the heart and soul of this Royal Commission. You are the key to its success.[7]
>
> The Hon Ronald Sackville AO QC, Chair

Engagement

The Royal Commission understands the importance of hearing directly from people with disability about their experiences. There are a number of ways people with disability can share their experiences, including through submissions, public hearings, private sessions and participating in community engagement activities. The Royal Commission acknowledges that people with disability may be reluctant to share their experiences publicly and may have trauma connected with the violence, abuse, neglect or exploitation they have experienced. We are committed to ensuring that people with disability can share their experiences in whatever way best suits their individual needs (see Chapter 6, ‘Support for people engaging with the Royal Commission’).

We also know that some people may face greater barriers than others in engaging with us, and that we may need to go to them. This may be because of the setting in which they live or the nature of their disability. Ensuring that these people have the opportunity to engage with us is of paramount importance to our work.

To that end, we are continuing to explore the ways in which people can be supported to share their experiences with the Royal Commission. This includes being able to provide submissions in a range of formats and languages, adjustments to physical or virtual environments, and a support person where appropriate.

The information we gather through our engagement activities informs our work in a range of ways. This includes by shaping the focus of our public hearings, informing our policy work and research programs, and assisting us as we develop recommendations. Our engagement work is also critical to helping us check that we are on the right track and that we are reaching out to as many people with disability as possible. We will remain flexible and continue to refine the issues and themes we examine according to what people with disability are telling us.

Submissions

Submissions are an important way for us to hear from people with disability, their friends, families and supporters, and representative organisations, as outlined in Chapter 8, ‘Submissions’. Each submission helps inform our inquiry and final report.

Submissions can be provided to the Royal Commission in a range of formats and in any language. We will publicise the closing date for submissions well in advance.

The Royal Commission will continue to draw on submissions about the experiences of people with disability, their hopes for the future and practical suggestions for change to inform the recommendations and solutions we put forward in the final report. In one submission, a person with disability said:

> I hope for proper procedures to put in place so that what I have experienced in the past does not happen to people in the future ... I hope that the socio-economic and geographic situation of individuals no longer determines the quality of assistance that is provided.[8]

For information about making a submission, please visit our website.[9]

Private sessions

Private sessions are another way for us to hear directly from people with disability. They allow people to share their experiences with the Royal Commission in a confidential setting. They are discussed in Chapter 10, ‘Private sessions’.

We will continue to listen to people’s experiences and seek to understand their aspirations and suggestions for change through our private sessions.

For information on how to register for a private session, please visit our website.[10]

Community engagement

As outlined in Chapter 9, ‘Community engagement’, people with disability and their supporters have been sharing their experiences, what matters to them, and suggestions for reform with Commissioners at community forums. At our community forum in Adelaide, South Australia, in 2019, one participant said:

> Ableism is the foundation of our oppression and consequent suffering, and it’s – the consequent ableist attitudes and behaviours of the community generally. The deadly bigotry of low expectations and the consequences over a lifetime are killers.[11]

We suspended community forums due to the COVID-19 pandemic. Once it is safe to resume, we anticipate holding more community forums in metropolitan and regional locations across Australia. The Royal Commission will prioritise holding these in states and territories where we have not yet held face-to-face engagement activities. We will keep people aware of our engagement activities, for example, by publishing information about community forums on our website, via the Royal Commission mailing list and on our social media channels.

We will continue to hold targeted engagements, drawing on the expertise of people with disability and key stakeholders to inform our policy work. At our co-designed online engagement with Speak Out self-advocates in May 2020, one participant told us that she was concerned about the treatment of group home residents during the COVID-19 pandemic. She said: 'I am concerned about some friends in group homes that have not been able to see people and have also been locked, locked in.'[12]

In Chapter 9, we outlined our intention to engage with residents of group homes. We will also reach out to people with disability in other closed environments, including prisons, forensic mental health and forensic disability facilities, and youth detention centres. We will engage with people in day programs and segregated employment settings to ensure they have the opportunity to participate in our inquiry.

We will work with First Nations communities and culturally and linguistically diverse people with disability, representative organisations and advocacy groups to ensure there are accessible pathways for involvement in our work. We will seek to engage directly with children and young people with disability and women and girls with disability.

Hearings

We will continue to hold public hearings across Australia to gather evidence of the violence, abuse, neglect and exploitation experienced by people with disability; best practice in preventing, reporting, investigating and responding to those experiences; and suggestions on what should be done to create a more inclusive society. Public hearings play an essential role in our work, including by increasing community awareness of the experiences of people with disability and obtaining evidence that can be used to make findings and inform the recommendations in our final report.

In March 2020, the Royal Commission suspended public hearings due to the COVID-19 pandemic. Our public hearing program, with appropriate adjustments to ensure the safety of all participants, resumed in August 2020. The program began with a hearing about the experiences of people with disability during the ongoing COVID-19 pandemic, as at August 2020.

Our hearings for the rest of 2020 will focus on the following subjects:

- Public hearing 6: Psychotropic medication, behaviour support and behaviours of concern
- 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 8: The experiences of First Nations people with disability and their families in contact with child protection systems
- Public hearing 9: Systemic barriers in the pathways to employment for people with disability
- Public hearing 10: Training and education of health care professionals in relation to people with cognitive disability.

Chapter 7, ‘Public hearings’ outlines the hearings we have held to date, other than the COVID-19 hearing, as well as planned future hearings.

We intend to release reports of each public hearing, which may include findings made by Commissioners based on evidence obtained at the hearing as well as areas for further enquiry.

Our public hearings will advance our understanding of the nature and extent of violence against, and abuse, neglect and exploitation of, people with disability; bear witness to people’s experiences in a public forum; and enhance the understanding of the Royal Commission and the broader community of systemic issues related to our terms of reference.

Policy, data and research

The Royal Commission has a broad policy, data and research program, which is described in more detail in Chapter 11, ‘Research and policy’. The program, which will support Commissioners in developing recommendations, draws on:

- evidence presented in public hearings and any relevant findings
- information gathered through submissions, responses to issues papers, private sessions and engagement activities
- data and research.

We will build on this evidence and information to understand the nature, drivers, extent and impact of violence, abuse, neglect and exploitation. We will also examine what we are being told about the practices that are working well, or hold promise.

Policy

> It's okay to talk about violence, abuse and neglect ... but a lot of people don't even realise they are victims. Education is key. We all need a standard of rights that we all must abide by. PWD [people with disability] have no idea what their rights even are the majority of the time.[13]

Our policy work focuses on understanding the systemic and structural issues that may drive or contribute to violence against, and abuse, neglect and exploitation of, people with disability in different settings and contexts. Many of the issues and themes we are examining are complex, with no single solution. Transformational change may require reform of different laws, policies, programs and practices across many policy areas.

Following the principle of 'nothing about us without us', people with disability have called for their participation in developing policies and practices that affect them across all settings and contexts.[14] One person with disability who responded to our *Emergency planning and response issues paper* said that governments should:

> include us in emergency planning by providing us with the opportunity and inviting us to speak about issues that affect us and solutions that will help and listen to what we have to say.[15]

Hearing directly from people with disability also guides our identification of key issues and development of recommendations. We release issues papers to seek information and advice from people with disability and others on specific topics. The issues papers provide individuals and organisations with the opportunity to contribute to our understanding of systemic issues.

In addition to issues papers, the Royal Commission will release discussion papers to gather more detailed information and advice from people with disability and other experts to identify and test possible solutions for the systemic issues that need to be addressed. Our discussion papers will explore the themes and issues we have identified from our work so far, which are outlined in Chapter 17 and Chapter 18.

For information on how to access and respond to our policy papers, visit the Royal Commission website.[16]

Data and research

From the outset, the Royal Commission recognised the importance of a comprehensive research agenda to inform our inquiry. As set out in Chapter 11, our research program is designed to provide an evidence base to support our work and recommendations. It includes a review and synthesis of existing research and commissioning of primary research projects to address key gaps related to our terms of reference. We will also conduct an in-depth analysis of past reports and inquiries that are relevant to our work.

Our future research will include projects examining:

- the nature and extent of violence against, and abuse, neglect and exploitation of, people with disability
- factors that help protect against, or increase the risk of, violence against, and abuse, neglect and exploitation of, people with disability
- barriers to identifying, investigating, reporting and responding to violence against, and abuse, neglect and exploitation of, people with disability
- what we can learn from domestic and international best practice and other innovative and emerging ways of promoting an inclusive society to reduce the risk of violence against, and abuse, neglect and exploitation of, people with disability.

We will also have a focus on research that describes and analyses the specific experiences of:

- young people with disability
- women and girls with disability
- LGBTIQ+ people with disability
- First Nations people with disability
- culturally and linguistically diverse people with disability
- people with complex needs.

Our data and analytics program obtains, compiles and analyses datasets to aid our understanding of the extent of violence against, and abuse, neglect and exploitation of, people with disability. Through this work, the Royal Commission aims to establish a baseline against which change can be measured. Our data and analytics program will focus on areas including:

- the use of data at the NDIS Quality and Safeguards Commission
- barriers to using standard questions to identify people with disability
- the way the National Disability Data Asset could be used to track violence against, and abuse, neglect and exploitation of, people with disability
- publishing data disaggregated by disability status
- exploring how recommendations from past inquiries and reviews about data have been followed.

The projects set out in our research agenda will provide a comprehensive evidence base for the Royal Commission's recommendations. They will comprise a legacy of disability research that addresses gaps in our understanding of the factors that contribute to the violence, abuse, neglect and exploitation that people with disability face. Our peer-reviewed research reports will be published on our website.[17]

Our final report and recommendations

At the end of the Royal Commission's inquiry, our final report must identify best practices and recommend changes to laws, policies, practices and systems to prevent or, where it occurs, respond to violence, abuse, neglect and exploitation experienced by people with disability.

As discussed in Chapter 3, the Royal Commission has the power to make recommendations we consider appropriate, including any necessary policy, legislative, administrative or structural reforms.[18] Our recommendations will focus on addressing systemic issues that drive violence against, and abuse, neglect and exploitation of, people with disability, while being informed by individual experiences of people with disability.[19] The recommendations will be underpinned by evidence from public hearings and our policy, data and research program, and designed as practical, evidence-based actions that will achieve measurable change in the areas set out in our terms of reference.

In Part D, 'Emerging themes and our future direction', we highlighted the importance of our ongoing work on attitudes towards disability. Changing hearts, minds and attitudes in the community is fundamental to our task of promoting a more inclusive society that supports the independence of people with disability and their right to live free from violence, abuse, neglect and exploitation. It is essential that our recommendations also change the values and standards the community expects to be upheld for people with disability.

While we will make recommendations for necessary reforms, the Royal Commission alone cannot bring about the change needed to address the problems faced by people with disability. It will be up to governments, institutions and the community to embrace the call for change and implement our recommendations.

> My hope for future is that people with disabilities are valued in the community & genuinely treated equally.[20]

Endnotes

1 *Letters Patent* (Cth), 4 April 2019 amended 13 September 2019.
2 Transcript, Sam Petersen, Public hearing 3, 6 December 2019, P-439 [14–15].
3 *Letters Patent* (Cth), 4 April 2019 amended 13 September 2019.
4 *Letters Patent* (Cth), 4 April 2019 amended 13 September 2019, (s).
5 *Letters Patent* (Cth), 4 April 2019 amended 13 September 2019, (g).
6 *Letters Patent* (Cth), 4 April 2019 amended 13 September 2019, (c).
7 Transcript, the Chair, Public hearing 1, 16 September 2019, P-15 [16–18].
8 Name withheld, Submission, 5 March 2020.
9 'Make your submission', *Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability*, webpage. <www.disability.royalcommission.gov.au/share-your-story/make-your-submission>
10 'Apply for a private session', *Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability*, webpage. <www.disability.royalcommission.gov.au/share-your-story/apply-private-session>
11 Glenda Lee, Royal Commission community forum, 12 November 2019.
12 Name withheld, Royal Commission targeted engagement with Speak Out advocates, May 2020.
13 Name withheld, Submission in response to *Rights and attitudes issues paper*, 22 May 2020.
14 James Charlton, *Nothing about us without us: Disability oppression and empowerment*, University of California Press, 2000.
15 Name withheld, Submission in response to *Emergency planning and responses issues paper*, 1 May 2020.
16 'Issues papers', *Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability*, webpage. <www.disability.royalcommission.gov.au/policy-and-research/issues-papers>
17 'Research program', *Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability*, webpage. <www.disability.royalcommission.gov.au/policy-and-research/research-program>
18 *Letters Patent* (Cth), 4 April 2019 amended 13 September 2019, recitals.
19 *Letters Patent* (Cth), 4 April 2019 amended 13 September 2019, (l).
20 Name withheld, Submission, 20 February 2020.

June and Charlie*

June is profoundly deaf, has low vision and has significant physical disabilities. She has a son, Charlie, who is in his twenties. Charlie was born with physical disabilities and is autistic.

June told us she encounters abuse in the community on a regular basis. This abuse can range from name-calling and refusal of service to actual physical violence. She explained:

> Due to being deaf and having a limited range of vision, I am unaware of people who are behind me or coming from the side. I have had experiences where I have been rammed by shopping trolleys, had people take control of my wheelchair and slam [it] into a wall to get me out of their way; and been regularly physically assaulted by people slapping, punching, spitting and hitting me with objects; whilst verbally abusing me.

June recalled an incident in a queue at the post office:

> A man leaned over the back of my chair in order to be served first … he placed his hand inside my blouse and bra and fondled my breast. Not knowing what to do, I fled.

While June was outside in tears, a witness flagged down passing police. June gave the police a statement of what happened, and the witness gave a description of the man. Police tracked him down quickly.

When the police spoke to the man, he denied what he had done. He said he wanted to charge June with assault because, he claimed, she had run over his toes with her wheelchair. The police took June home and spoke with her husband. They didn't have an interpreter and didn't speak to June – only to her husband. 'They told him', June said, 'that he needed to teach me better how to behave in public and learn to control my wheelchair in future.'

Charlie also experienced abuse and neglect in the mainstream school he attended.

June recounted that when Charlie was six a teacher put him in a wheelie bin with the lid closed because he was annoyed by Charlie's repetitive verbal behaviours. The teacher sat on the bin for half an hour. Charlie passed out. He was then suspended for a month for inappropriate behaviour towards a teacher. Two days later, Charlie attempted suicide – the first of many attempts.

June told us that during Charlie's schooling, teachers routinely excluded and isolated him. He was banned from all school camps, excursions and out-of-school activities. He was banned from taking a number of subjects. He was banned from the playground and was made to sit outside the staffroom during all breaks for all 12 years of his schooling.

For five years of his schooling Charlie was on a restricted enrolment, which meant he could attend school as little as three hours a week. June said she believes that this was because schools were unwilling to fund the support Charlie required, even though they collected enrolment and specialised funding for him as a full-time student.

June said that the abuse and neglect she and her son have experienced is 'minor' compared with the abuse others have suffered. She told us:

> It is my hope that this Commission will finally give a voice to people with disabilities, so that we may receive better treatment in our own homes, the community, places of employment and educational settings.

*** Names changed and some details removed to protect people's identities. Narrative based on a submission to the Royal Commission.**

Appendix A: Letters patent

The letters patent are the official documents that create a royal commission, appoint the commissioners and, in the terms of reference, define the nature and scope of the inquiry.[1]

This Appendix contains the Commonwealth letters patent issued on 4 April 2019 establishing the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, and the amended letters patent issued on 13 September 2019.

Each state government in Australia has also issued letters patent establishing the Royal Commission under state legislation.[2] These letters patent are in substantially the same terms as those issued by the Commonwealth. The state letters patent are available on the Royal Commission website.[3]

Commonwealth letters patent – issued 4 April 2019

ELIZABETH THE SECOND, by the Grace of God Queen of Australia and Her other Realms and Territories, Head of the Commonwealth

TO

The Honourable Ronald Sackville AO QC,

Ms Barbara Bennett PSM,

Dr Rhonda Louise Galbally AC,

Ms Andrea Jane Mason OAM,

Mr Alastair James McEwin, and

The Honourable John Francis Ryan AM

GREETING

RECOGNISING that people with disability are equal citizens and have the right to the full and equal enjoyment of all human rights and fundamental freedoms, including respect for their inherent dignity and individual autonomy.

AND that people with disability have the same rights as other members of Australian society to live and participate in safe environments free from violence, abuse, neglect and exploitation.

AND all forms of violence against, and abuse, neglect and exploitation of, people with disability are abhorrent.

AND Australia has international obligations to take appropriate legislative, administrative and other measures to promote the human rights of people with disability, including to protect people with disability from all forms of exploitation, violence and abuse under the Convention on the Rights of Persons with Disabilities.

AND to give effect to those obligations and broader responsibilities to all Australians, all Australian Governments provide funding and services for people with disability, and have implemented laws to protect and enhance the wellbeing of people with disability.

AND it is important that violence against, and abuse, neglect and exploitation of, people with disability in all settings and contexts are exposed and examined, including through the sharing of individual experiences.

AND it is important that people with disability are central to processes that inform best practice decision-making on what all Australian Governments and others can do to prevent and respond to violence against, and abuse, neglect and exploitation of, people with disability.

AND all Australian Governments have expressed their support for, and undertaken to cooperate with, your inquiry.

NOW THEREFORE We do, by these Our Letters Patent issued in Our name by Our Governor-General of the Commonwealth of Australia on the advice of the Federal Executive Council and under the Constitution of the Commonwealth of Australia, the *Royal Commissions Act 1902* and every other enabling power, appoint you to be a Commission of inquiry, and require and authorise you to inquire into the following matters:

(a) what governments, institutions and the community should do to prevent, and better protect, people with disability from experiencing violence, abuse, neglect and exploitation, having regard to the extent of violence, abuse, neglect and exploitation experienced by people with disability in all settings and contexts;

(b) what governments, institutions and the community should do to achieve best practice to encourage reporting of, and effective investigations of and responses to, violence against, and abuse, neglect and exploitation of, people with disability, including addressing failures in, and impediments to, reporting, investigating and responding to such conduct;

(c) what should be done to promote a more inclusive society that supports the independence of people with disability and their right to live free from violence, abuse, neglect and exploitation;

(d) any matter reasonably incidental to a matter referred to in paragraphs (a) to (c) or that you believe is reasonably relevant to your inquiry.

AND We direct you to make any recommendations arising out of your inquiry that you consider appropriate, including recommendations about any policy, legislative, administrative or structural reforms.

AND, without limiting the scope of your inquiry or the scope of any recommendations arising out of your inquiry that you may consider appropriate, We direct you, for the purposes of your inquiry and recommendations, to have regard to the following matters:

(e) all forms of violence against, and abuse, neglect and exploitation of, people with disability, whatever the setting or context;

(f) all aspects of quality and safety of services, including informal supports, provided by governments, institutions and the community to people with disability, including the National Disability Insurance Scheme (NDIS) and the NDIS Quality and Safeguarding Framework agreed by all Australian Governments in 2017;

(g) the specific experiences of violence against, and abuse, neglect and exploitation of, people with disability are multilayered and influenced by experiences associated with their age, sex, gender, gender identity, sexual orientation, intersex status, ethnic origin or race, including the particular situation of Aboriginal and Torres Strait Islander people and culturally and linguistically diverse people with disability;

(h) the critical role families, carers, advocates, the workforce and others play in providing care and support to people with disability;

(i) examples of best practice and innovative models of preventing, reporting, investigating or responding to violence against, and abuse, neglect or exploitation of, people with disability;

(j) the findings and recommendations of previous relevant reports and inquiries.

AND We further declare that you are not required by these Our Letters Patent to inquire, or to continue to inquire, into a particular matter to the extent that you are satisfied that the matter has been, is being, or will be, sufficiently and appropriately dealt with by the Royal Commission into Aged Care Quality and Safety, another inquiry or investigation, or a criminal or civil proceeding.

AND, without limiting the scope of your inquiry or the scope of any recommendations arising out of your inquiry that you may consider appropriate, We direct you, for the purposes of your inquiry and recommendations, to consider the following matters, and We authorise you, as you consider appropriate, having regard to the date by which you are required to submit your final report, to take (or refrain from taking) any action arising out of your consideration:

(k) the need to establish accessible and appropriate arrangements for people with disability, and their families, carers and others, to engage with your inquiry and to provide evidence to you, and share information with you, about their experiences;

(l) the need to focus your inquiry and recommendations on systemic issues, recognising nevertheless that you will be informed by individual experiences and may need to make referrals to appropriate authorities;

(m) the need to establish mechanisms to facilitate the timely communication of information, or the furnishing of evidence, documents or things, in accordance with section 6P of the *Royal Commissions Act 1902* or any other relevant law, including, for example, for the purpose of enabling the timely investigation and prosecution of offences or assisting an inquiry on a related matter by the Royal Commission into Aged Care Quality and Safety;

(n) the need to ensure that evidence that may be received by you that identifies particular individuals as having been subject to violence, abuse, neglect or exploitation is dealt with in a way that does not prejudice current or future criminal or civil proceedings or other contemporaneous inquiries;

(o) the need to establish appropriate arrangements in relation to current and previous inquiries, in Australia and elsewhere, for evidence and information to be shared with you in ways consistent with relevant obligations so that the work of those inquiries, including, with any necessary consents, the testimony of witnesses, can be taken into account by you in a way that avoids unnecessary duplication, improves efficiency and avoids unnecessary trauma to witnesses.

AND We appoint you, the Honourable Ronald Sackville AO QC, to be the Chair of the Commission.

AND We declare that you are a relevant Commission for the purposes of sections 4 and 5 of the *Royal Commissions Act 1902.*

AND We declare that you are a Royal Commission to which item 5 of the table in subsection 355-70(1) in Schedule 1 to the *Taxation Administration Act 1953* applies.

AND We declare that you are authorised to conduct your inquiry into any matter under these Our Letters Patent in combination with any inquiry into the same matter, or a matter related to that matter, that you are directed or authorised to conduct by any Commission, or under any order or appointment, made by any of Our Governors of the States or by the Government of any of Our Territories.

AND We declare that in these Our Letters Patent:

Convention on the Rights of Persons with Disabilities means the Convention on the Rights of Persons with Disabilities, done at New York on 13 December 2006.

government means the Government of the Commonwealth or of a State or Territory or a local government.

people with disability means people with any kind of impairment, whether existing at birth or acquired through illness, accident or the ageing process, including cognitive impairment and physical, sensory, intellectual and psycho-social disability.

Royal Commission into Aged Care Quality and Safety means the Royal Commission into Aged Care Quality and Safety issued by the Governor-General by Letters Patent on 8 October 2018 (and including any later variations of those Letters Patent).

AND We:

(p) require you to begin your inquiry as soon as practicable; and

(q) require you to make your inquiry as expeditiously as possible; and

(r) require you to submit to Our Governor-General an interim report that you consider appropriate not later than 30 October 2020; and

(s) require you to submit to Our Governor-General a report of the results of your inquiry, and your recommendations, not later than 29 April 2022.

IN WITNESS, We have caused these Our Letters to be made Patent.

WITNESS General the Honourable Sir Peter Cosgrove AK MC (Ret'd),
Governor-General of the Commonwealth of Australia.

Dated 4th April 2019

[Signed]

Governor-General

By His Excellency's Command

[Signed]

Prime Minister

Commonwealth letters patent – amended 13 September 2019

ELIZABETH THE SECOND, by the Grace of God Queen of Australia and Her other Realms and Territories, Head of the Commonwealth

TO

The Honourable Ronald Sackville AO QC,

Ms Barbara Bennett PSM,

Dr Rhonda Louise Galbally AC,

Ms Andrea Jane Mason OAM,

Mr Alastair James McEwin AM,

The Honourable John Francis Ryan AM, and

The Honourable Roslyn Gay Atkinson AO

GREETING

WHEREAS, by Letters Patent issued in Our name and entered in the Register of Patents on 4 April 2019, We appointed you (the ***initial members***):

(a) The Honourable Ronald Sackville AO QC; and

(b) Ms Barbara Bennett PSM; and

(c) Dr Rhonda Louise Galbally AC; and

(d) Ms Andrea Jane Mason OAM; and

(e) Mr Alastair James McEwin AM; and

(f) The Honourable John Francis Ryan AM;

to be a Commission of inquiry, required and authorised to inquire into certain matters, and required to submit to Our Governor-General a report of the results of that inquiry, and recommendations, not later than 29 April 2022;

AND WHEREAS it is desired to amend Our Letters Patent;

NOW THEREFORE We do, by these Our Letters Patent issued in Our name by Our Governor-General of the Commonwealth of Australia on the advice of the Federal Executive Council and under the Constitution of the Commonwealth of Australia, the *Royal Commissions Act 1902* and every other enabling power, amend those Letters Patent:

(g) by appointing you, the Honourable Roslyn Gay Atkinson AO, to be an additional member of this Commission of inquiry; and

(h) so that those Letters Patent apply to you in a corresponding way to the way those Letters Patent apply to each of the initial members who is not the Chair of this Commission of inquiry; and

(i) by inserting the following paragraphs after the paragraph "AND We appoint you, the Honourable Ronald Sackville AO QC, to be the Chair of the Commission." in those Letters Patent:

"AND We direct that the Chair be responsible for ensuring the effective, orderly and expeditious conduct of the inquiry in all its facets.

AND, without limiting the generality of the immediately preceding responsibility and as required during the conduct of your inquiry, We further direct that, other than making recommendations arising out of the inquiry and reporting on matters within these terms of reference, the Chair is authorised to give binding directions to, assign duties or functions to, or restrict the duties or functions of, other appointed Commissioners.".

IN WITNESS, We have caused these Our Letters to be made Patent.

WITNESS General the Honourable David Hurley AC DSC (Retd),
Governor-General of the Commonwealth of Australia.

Dated 13 September 2019

[Signed]

Governor-General

By His Excellency's Command

[Signed]

Prime Minister

Endnotes

1 *Royal Commissions Act 1902* (Cth), s 1A.

2 Original Letters Patent dated 17 April 2019 (NSW), 20 May 2019 (Tas), 4 June 2019 (Vic), 20 June 2019 (SA), 27 June 2019 (Qld) and 20 August 2019 (WA). Amended Letters Patent dated 2 October 2019 (NSW), 10 October 2019 (Qld), 24 October 2019 (SA), 28 October 2019 (Tas), 29 October 2019 (WA) and 6 November 2019 (Vic). The relevant State Acts establishing the Royal Commission include the *Royal Commissions Act 1902* (Cth), *Royal Commissions Act 1923* (NSW), *Commissions of Inquiry Act 1950* (Qld), *Royal Commissions Act 1917* (SA), *Commissions of Inquiry Act 1995* (Tas), *Inquiries Act 2014* (Vic) and *Royal Commissions Act 1968* (WA).

3 'Our terms of reference', *Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability*. <https://disability.royalcommission.gov.au/about-royal-commission/our-terms-reference>

Appendix B: Past reports and inquiries

National | Australian Capital Territory | New South Wales | Northern Territory
Queensland | South Australia | Tasmania | Victoria | Western Australia
United Nations | Other

National

Report no	Report citation
1	Auditor-General of Australia, *Management of agreements for disability employment services: Department of Social Services*, Auditor-General report no 45, June 2020.
2	Joint Standing Committee on the National Disability Insurance Scheme, Parliament of Australia, *Supported independent living*, May 2020.
3	Australia's National Research Organisation for Women's Safety (ANROWS), *Preventing gender-based violence in mental health inpatient units: Key findings and future directions*, Research to policy and practice paper, Issue 1, January 2020.
4	The Social Deck, *Right to opportunity: Consultation report to help shape the next national disability strategy*, Report prepared for the Australian Government Department of Social Services, December 2019.
5	Joint Standing Committee on the National Disability Insurance Scheme, Parliament of Australia, *NDIS planning interim report*, December 2019.
6	David Tune, *Review of the National Disability Insurance Scheme Act 2013: Removing red tape and implementing the NDIS participant service guarantee*, Report commissioned by the Australian Minister for the National Disability Insurance Scheme, December 2019.
7	Jim Watterston & Megan O'Connell, *Those who disappear: The Australian education problem nobody wants to talk about*, Melbourne Graduate School of Education Industry report no 1, November 2019.
8	Disabled People's Organisations Australia and National Women's Alliances, *The status of women and girls with disability in Australia*, Joint position paper to the Commission on the Status of Women, November 2019.
9	National Children's Commissioner, Australian Human Rights Commission, *Children's rights report 2019: In their own right*, October 2019.
10	Australian Civil Society CRPD Shadow Report Working Group, *Disability rights now 2019: Australian civil society shadow report to the United Nations Committee on the Rights of Persons with Disabilities: UN CRPD Review 2019*, Report in response to the list of issues prior to the submission of the combined second and third periodic reports of Australia [CRPD/C/AUS/QPR/2–3], July 2019.
11	Australian Institute of Health and Welfare, *The health of Australia's prisoners 2018*, May 2019.

Report no	Report citation
12	Australian Law Reform Commission, *Family law for the future – An inquiry into the family law system*, Final report, ALRC report 135, March 2019.
13	Kathleen Flanagan, Andrew Beer, Julia Verdouw, Braam Lowies, Elizabeth Hemphill & Gina Zappia, *Understanding specialist disability accommodation funding*, Australian Housing and Urban Research Institute final report no 310, March 2019.
14	Joint Standing Committee on the National Disability Insurance Scheme, Parliament of Australia, *General issues around the implementation and performance of the NDIS*, Progress report, March 2019.
15	Refugee Council of Australia, *Barriers and exclusions: The support needs of newly arrived refugees with a disability*, March 2019.
16	Senate Community Affairs References Committee, Parliament of Australia, *Support for Australia's thalidomide survivors*, Final report, March 2019.
17	Australian Government Productivity Commission, *Review of the National Disability Agreement*, Study report, February 2019.
18	Angela Dew, Rebecca Barton, Vicki Flood, John Gilroy, Heather Jensen, Michelle Lincoln, Kim McRae, Lee Ryall, Margaret Smith & Kerry Taylor, Ngaanyatjarra Pitjantjatjara Yankunytjatjara Women's Council, *Looking after children with disabilities from the NPY Lands*, 2019.
19	Mikala Sedgwick, Elizabeth Pellicano & Rozanna Lilley, *'We look after our own mob': Aboriginal and Torres Strait Islander experiences of autism*, 2019.
20	Australian Government Department of Social Services, *Community visitor schemes review*, Final report for the Disability Reform Council (Council of Australian Governments), December 2018.
21	Employment Services Expert Advisory Panel, *I want to work: Employment Services 2020 Report*, Report commissioned by the Australian Government, December 2018.
22	Joint Standing Committee on the National Disability Insurance Scheme, Parliament of Australia, *NDIS ICT systems*, December 2018.
23	Joint Standing Committee on the National Disability Insurance Scheme, Parliament of Australia, *Provision of assistive technology under the NDIS*, Final report, December 2018.
24	Senate Community Affairs References Committee, Parliament of Australia, *Accessibility and quality of mental health services in rural and remote Australia*, December 2018.
25	Settlement Services International*, Still outside the tent: Cultural diversity and disability in a time of reform – a rapid review of evidence*, Occasional paper no 2, November 2018.
26	Joint Standing Committee on the National Disability Insurance Scheme, Parliament of Australia, *Market readiness for provision of services under the NDIS*, September 2018.

Report no	Report citation
27	Australian Government Department of Infrastructure, Regional Development and Cities, *Third review of the Disability Standards for Accessible Public Transport 2002 (Transport Standards)*, Issues paper, August 2018.
28	The Justice Project, Law Council of Australia, '*People with disability*' in Final report – Part 1, August 2018.
29	Social Compass, *NDIS East Arnhem co-design project evaluation - Final Report*, Report prepared for the Australian Government Department of the Prime Minister and Cabinet, June 2018.
30	Australian Human Rights Commission, *A future without violence: Quality, safeguarding and oversight to prevent and address violence against people with disability in institutional settings*, June 2018.
31	Joint Standing Committee on the National Disability Insurance Scheme, Parliament of Australia, *The provision of hearing services under the National Disability Insurance Scheme (NDIS)*, June 2018.
32	Claire Spivakovsky, Janemaree Maher, Jude McCulloch, Jasmine McGowan, Kara Beavis, Meredith Lea, Jess Cadwallader & Therese Sands, *Women, disability and violence: Barriers to accessing justice: Final report*, ANROWS Horizons Series, Issue 2, March 2018.
33	Human Rights Watch, *'I needed help but instead I was punished': Abuse and neglect of prisoners with disabilities in Australia*, February 2018.
34	Joint Standing Committee on the National Disability Insurance Scheme, Parliament of Australia, *Transitional arrangements for the NDIS*, February 2018.
35	Megan Moskos, Kostas Mavromaras, Stephane Mahuteau, Linda Isherwood, Alison Goode, Helen Walton, Llainey Smith, Zhang Wei & Joanne Flavel, *Evaluation of the NDIS*, National Institute of Labour Studies, Flinders University, Final report, 2018.
36	Department of Developmental Disability Neuropsychiatry, University of New South Wales, *Recommendations from the national roundtable on the mental health of people with intellectual disability*, 2018.
37	Australian Law Reform Commission, *Pathways to justice – An inquiry into the incarceration rate of Aboriginal and Torres Strait Islander peoples*, Final report, ALRC report 133, December 2017.
38	Joint Standing Committee on the National Disability Insurance Scheme, Parliament of Australia, *Provision of services under the NDIS Early Childhood Early Intervention Approach*, December 2017.
39	Royal Commission into Institutional Responses to Child Sexual Abuse, *Final report*, December 2017.

Report no	Report citation
40	Anne Graham, Sally Robinson, Karen Fisher, Ariella Meltzer, Megan Blaxland & Kelley Johnson, *Preventing abuse and promoting personal safety in young people with disability*, Final report prepared by the Centre for Children and Young People, November 2017.
41	Senate Community Affairs References Committee, Parliament of Australia, *Delivery of outcomes under the National Disability Strategy 2010–2020 to build inclusive and accessible communities*, November 2017.
42	Australian Government Productivity Commission, *National Disability Insurance Scheme (NDIS) costs*, Study report, October 2017.
43	Australian Government Productivity Commission, *Introducing competition and informed user choice into human services: Reforms to human services*, Inquiry report no 85, October 2017.
44	Australian NGO Coalition, *Australia's compliance with the International Convention on the Elimination of All Forms of Racial Discrimination*, Submission to the United Nations Committee on the Elimination of Racial Discrimination, October 2017.
45	Joint Standing Committee on the National Disability Insurance Scheme, Parliament of Australia, *General issues around the implementation and performance of the NDIS*, Progress report, September 2017.
46	Patsie Frawley, Sally Robinson & Sue Dyson, *'Whatever it takes': Access for women with disabilities to domestic and family violence services*, Final report, ANROWS Horizons series, Issue 5, August 2017.
47	Joint Standing Committee on the National Disability Insurance Scheme, Parliament of Australia, *Provision of services under the NDIS for people with psychosocial disabilities related to a mental health condition*, August 2017.
48	Australian Law Reform Commission, *Elder abuse – A national legal response*, Final report, ALRC report 131, June 2017.
49	Royal Commission into Institutional Responses to Child Sexual Abuse, *Report of case study no 41: Institutional responses to allegations of the sexual abuse of children with disability*, May 2017.
50	Royal Commission into Institutional Responses to Child Sexual Abuse, *Criminal justice report*, 2017.
51	Senate Community Affairs References Committee, Parliament of Australia, *Indefinite detention of people with cognitive and psychiatric impairment in Australia*, November 2016.
52	Australian Human Rights Commission, *Willing to work: National Inquiry into Employment Discrimination Against Older Australians and Australians with Disability*, May 2016.
53	Joint Standing Committee on the National Disability Insurance Scheme, Parliament of Australia, *Accommodation for people with disabilities and the NDIS*, May 2016.

Report no	Report citation
54	National Disability Services, *Speaking up about safety: Perspectives of people with disability on personal safety at home, in the community and in disability services*, May 2016.
55	Australian Government Department of Industry, Innovation and Science, *Review of the Disability (Access to Premises – Buildings) Standards 2010*, First review, April 2016.
56	Senate Education and Employment References Committee, Parliament of Australia, *Access to real learning: The impact of policy, funding and culture on students with disability*, January 2016.
57	Ernst & Young, *Independent review of the NDIS Act*, Report commissioned by the Australian Government Department of Social Services, December 2015.
58	Senate Community Affairs References Committee, *Violence, abuse and neglect against people with disability in institutional and residential settings, including the gender and age related dimensions, and the particular situation of Aboriginal and Torres Strait Islander people with disability, and culturally and linguistically diverse people with disability*, November 2015.
59	Sue Leahy, Jade Maloney, Sharon Floyd, Andrew Hawkins, Jennifer Engels, Alexandra Ellinson & Jasper Odgers (ARTD Consultants), *National Disability Insurance Scheme Quality and Safeguarding Framework*, Consultation report prepared for the Australian Government Department of Social Services, August 2015.
60	Senate Community Affairs References Committee, Parliament of Australia, *Out of home care*, August 2015.
61	Urbis, *2015 review of the Disability Standards for Education 2005*, Final report commissioned by the Australian Government Department of Education and Training, July 2015.
62	Senate Community Affairs References Committee, Parliament of Australia, *Adequacy of existing residential care arrangements available for young people with severe physical, mental or intellectual disabilities in Australia*, Inquiry final report, June 2015.
63	Royal Commission into Institutional Responses to Child Sexual Abuse, *Report of case study no 9: The responses of the Catholic Archdiocese of Adelaide, and the South Australian Police, to allegations of child sexual abuse at St Ann's Special School*, May 2015.
64	Reference Group on Welfare Reform, *A new system for better employment and social outcomes*, Report to the Australian Minister for Social Services, Final report, February 2015.
65	Children with Disability Australia, *Post school transition: The experiences of students with disability*, 2015.

Report no	Report citation
66	Australian Government Productivity Commission, *Access to justice arrangements*, Inquiry report vol 1, no 72, September 2014.
67	Australian Government Productivity Commission, *Access to justice arrangements*, Inquiry report vol 2, no 72, September 2014.
68	Senate Community Affairs References Committee, Parliament of Australia, *Bridging our growing divide: Inequality in Australia – The extent of income inequality in Australia*, December 2014.
69	Women with Disabilities Australia, First People's Disability Network Australia, People with Disability Australia, Children with Disability Australia & National Ethnic Disability Alliance, *Joint submission from National Cross-Disability Disable People's Organisations*, Submission to the Senate inquiry into domestic violence in Australia, September 2014.
70	Australian Law Reform Commission, *Equality, capacity and disability in Commonwealth laws*, Final report, ALRC report 124, August 2014.
71	Australian Human Rights Commission, *KA, KB, KC and KD v Commonwealth of Australia: Report into arbitrary detention, inhumane conditions of detention and the right of people with disabilities to live in the community with choices equal to others*, AusHRC 80, September 2014.
72	Senate Community Affairs References Committee, Parliament of Australia, *Prevalence of different types of speech, language and communication disorders and speech pathology services in Australia*, September 2014.
73	Royal Commission into Institutional Responses to Child Sexual Abuse, *Interim report*: Volume 1, June 2014.
74	Royal Commission into Institutional Responses to Child Sexual Abuse, *Interim report*: Volume 2, June 2014.
75	Senate Community Affairs References Committee, Parliament of Australia, *Care and management of younger and older Australians living with dementia and behavioural and psychiatric symptoms of dementia (BPSD)*, March 2014.
76	Australian Human Rights Commission, *Equal before the law: Towards disability justice strategies*, February 2014.
77	Australian Human Rights Commission, *The forgotten children: National inquiry into children in immigration detention*, 2014.

Report no	Report citation
78	Eileen Baldry, Ruth McCausland, Sarah Johnson & Anna Cohen, *People with mental health disorders and cognitive impairment in the criminal justice system: Cost-benefit analysis of early support and diversion*, Report based on a paper presented at the Australian Human Rights Commission and University of New South Wales 'Access to Justice in the Criminal Justice System for People with Disability' roundtable on 22 April 2013, August 2013.
79	Senate Community Affairs References Committee, Parliament of Australia, *Involuntary or coerced sterilisation of people with disabilities in Australia*, First report, July 2013.
80	Senate Legal and Constitutional Affairs References Committee, Parliament of Australia, *Value of a justice reinvestment approach to criminal justice in Australia*, June 2013.
81	Carers Australia, *Culturally and linguistically diverse carers in Australia*, Background report, 2013.
82	Mindy Sotiri, Patrick McGee & Eileen Baldry, *No end in sight: The imprisonment, and indefinite detention of Indigenous Australians with a cognitive impairment*, Report prepared by the Aboriginal Disability Justice Campaign for the National Justice Chief Executive Officers Working Group, September 2012.
83	Australian Human Rights Commission, *Australian study tour report – Visit of the UN Special Rapporteur on violence against women*, August 2012.
84	Australian Government Department of Education, Employment and Workplace Relations, *Report on the Review of Disability Standards for Education 2005*, June 2012.
85	PricewaterhouseCoopers (PwC), *Disability expectations: Investing in a better life, a stronger Australia*, November 2011.
86	Aboriginal and Torres Strait Islander Social Justice Commissioner, Australian Human Rights Commission, *Social justice report 2011*, October 2011.
87	Australian Government Productivity Commission, *Disability care and support,* Inquiry report vol 1, no 54, July 2011.
88	Australian Government Productivity Commission, *Disability care and support,* Inquiry report vol 2, no 54, July 2011.
89	Senate Community Affairs References Committee, Parliament of Australia, *Disability and ageing: Lifelong planning for a better future*, July 2011.
90	Senate Community Affairs References Committee, Parliament of Australia, *Hear us: Inquiry into hearing health in Australia*, May 2010
91	Joint Standing Committee on Migration, Parliament of Australia, *Enabling Australia: Inquiry into migration treatment of disability*, 2010.

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92	Allen Consulting Group, *Review of the Disability Standards for Accessible Public Transport*, Final report to the Australian Minister for Infrastructure, Transport, Regional Development and Local Government and the Attorney-General, October 2009.
93	Phillip French, Julie Dardel & Sonya Price-Kelly, *Rights denied: Towards a national policy agenda about abuse, neglect and exploitation of persons with cognitive impairment*, Report of joint project between People with Disability Australia and the Disability Studies and Research Centre, University of New South Wales, September 2009.
94	Senate Standing Committee on Community Affairs, Parliament of Australia, *Government expenditure on Indigenous affairs and social services in the Northern Territory*, December 2008.
95	Senate Standing Committee on Community Affairs, Parliament of Australia, *Building trust: Supporting families through disability trusts*, Inquiry report, October 2008.
96	Senate Standing Committee on Community Affairs, Parliament of Australia, *Towards recovery: Mental health services in Australia*, Inquiry report, September 2008.
97	Australian Human Rights Commission, *A last resort? National inquiry into children in immigration detention*, 2004.
98	Senate Employment, Workplace Relations and Education References Committee, Parliament of Australia, *Education of students with disabilities*, Inquiry report, December 2002.
99	Office of the Aboriginal and Torres Strait Islander Social Justice Commissioner, Australian Human Rights Commission, *Indigenous deaths in custody 1989 to 1996*, Report prepared for the Aboriginal and Torres Strait Islander Commission, 1996.
100	Royal Commission into Aboriginal Deaths in Custody, *National Report*, April 1991.

Australian Capital Territory

Report no	Report citation
101	Standing Committee on Education, Employment and Youth Affairs, Australian Capital Territory Legislative Assembly, *Inquiry into management and minimisation of bullying and violence in ACT schools,* Report no 6, September 2019.
102	Australian Capital Territory Government Department of Community Services, *Disability justice strategy 2019–2029: A strategy to address unequal access to justice in the ACT*, August 2019.
103	Women with Disabilities ACT, *Contraception, consent, respectful relationships & sexuality for women and girls, feminine identifying & non-binary people with disabilities in the ACT*, Final report, May 2019.
104	Australian Capital Territory Human Rights Commission, *Commission initiated review of allegations regarding Bimberi Youth Justice Centre*, Report of the ACT Disability and Community Services Commissioner and ACT Human Rights Commissioner, March 2019.
105	Australian Capital Territory Government, *Towards disability justice for the ACT: Summary of research and consultations*, 2019.
106	Standing Committee on Health, Ageing and Community Services, Legislative Assembly for the Australian Capital Territory, *Inquiry into the implementation, performance and governance of the National Disability Insurance Scheme in the ACT*, Report no 4, November 2018.
107	Standing Committee on Health, Ageing and Community Services, Legislative Assembly for the Australian Capital Territory, *Inquiry into the employment of people with disabilities*, Report no 2, August 2017.
108	Expert Panel on Students with Complex Needs and Challenging Behaviour, Australian Capital Territory Department of Education and Training, *Schools for all children and young people: Report of the Expert Panel on Students with Complex Needs and Challenging Behaviour*, November 2015.
109	Australian Capital Territory Human Rights Commission, *The ACT youth justice system 2011: A report to the ACT Legislative Assembly*, July 2011.
110	Standing Committee on Health, Community and Social Services, Legislative Assembly for the Australian Capital Territory, *Love has its limits – Respite care services in the ACT*, Report no 4, December 2010.

New South Wales

Report no	Report citation
111	New South Wales Ageing and Disability Commissioner, *Review into disability advocacy in NSW,* December 2019.
112	Megan Davis, *Family is culture: Independent review of Aboriginal children and young people in out-of-home care in NSW*, Final report, October 2019.
113	Portfolio Committee No. 2 – Health and Community Services, New South Wales Legislative Council, *Implementation of the National Disability Insurance Scheme and the provision of disability services in New South Wales*, Report 51, December 2018.
114	New South Wales Ombudsman, *Abuse and neglect of vulnerable adults in NSW – the need for action*, A special report to New South Wales Parliament under s 31 of the Ombudsman Act 1974 (NSW), November 2018.
115	New South Wales Ombudsman, *Report of reviewable deaths in: 2014 and 2015, 2016 and 2017 – Deaths of people with disability in residential care,* August 2018.
116	New South Wales Law Reform Commission, *Review of the Guardianship Act 1987*, Report no 145, May 2018.
117	Jackie Crowe, Murray Wright, Kevin Huckshorn, Karen Lenihan, Julie Mooney & Robyn Shields, *Review of seclusion, restraint and observations of consumers with a mental illness in NSW Health facilities*, Independent review for New South Wales Ministry of Health, December 2017.
118	Portfolio Committee No. 3 – Education, New South Wales Legislative Council, *Education of students with a disability or special needs in New South Wales*, Report no 37, September 2017.
119	New South Wales Ombudsman, *NSW Ombudsman inquiry into behaviour management in schools*, A special report to New South Wales Parliament under s 31 of the Ombudsman Act 1974 (NSW), August 2017.
120	First Peoples Disability Network Australia, *The Redfern statement: Disability workshop communique*, May 2017.
121	General Purpose Standing Committee No. 2, New South Wales Legislative Council, *Child protection*, Report 46, March 2017.
122	Vicki Sentas and Camilla Pandolfini, *Policing young people in NSW: A study of the Suspect Targeting Management Plan*, Report with the Youth Justice Coalition NSW, 2017.
123	Auditor-General of New South Wales, *Supporting students with disability in NSW public schools: Department of Education and Training*, July 2016.

Report no	Report citation
124	New South Wales Ombudsman, *Report of reviewable deaths in 2012 and 2013, Volume 2: Deaths of people with disability in residential care*, June 2015.
125	New South Wales Law Reform Commission, *People with cognitive and mental health impairments in the criminal justice system: Criminal responsibility and consequences*, Report no 138, May 2013.
126	KPMG, *Prevention of abuse and safeguarding mechanisms in ageing, disability and home care*, Report commissioned by the New South Wales Government Department of Family and Community Services, January 2013.
127	New South Wales Law Reform Commission, *People with cognitive and mental health impairments in the criminal justice system: Diversion*, Report no 135, June 2012.
128	New South Wales Ombudsman, *More than boarding and lodging: The need for boarding house reform*, A special report to New South Wales Parliament under s 31 of the Ombudsman Act 1974 (NSW), August 2011.
129	Standing Committee on Social Issues, New South Wales Legislative Council, *Substitute decision-making for people lacking capacity*, Report no 43, February 2010.
130	General Purpose Standing Committee No. 2, New South Wales Legislative Council, *The provision of education to students with a disability or special needs*, Report no 34, July 2010.
131	Auditor-General of New South Wales, *Educating primary school students with disabilities: Department of Education and Training*, September 2006.
132	New South Wales Law Reform Commission, *Blind or deaf jurors*, Report no 114, September 2006.
133	New South Wales Law Reform Commission, *Review of the Anti-Discrimination Act 1977 (NSW)*, Report no 92, November 1999.
134	New South Wales Law Reform Commission, *People with an intellectual disability and the criminal justice system*, Report no 80, December 1996.

Northern Territory

Report no	Report citation
135	Northern Territory Health and Community Services Complaints Commission, *De-identified investigation report – 1. Legal and rights issues related to: Consent – major medical procedures and electroconvulsive therapy (ECT); Use of sedation/restraint; Processes for authorisation of ECT; Documentation under the MHRSA. 2. Clinical appropriateness of ECT being undertaken when a patient has been kept sedated since the previous ECT session*, August 2019.
136	Social Policy Scrutiny Committee, Legislative Assembly of the Northern Territory, *Inquiry into the National Disability Insurance Scheme (Authorisations) Bill 2019*, Final report, May 2019.
137	David McGrath, Owen Samuels, Dannielle Nagle, Leanne Dowse and Ed Heffernan, *Report on the review of the forensic mental health and disability services within the Northern Territory*, Final report for the Northern Territory Government, January 2019.
138	PricewaterhouseCoopers Indigenous Consulting, *Engaging Aboriginal Community Controlled Organisations (ACCOs) in disability service provision in the NT*, September 2018.
139	Northern Territory Ombudsman, *Strangers in their own land: Use of Aboriginal interpreters by NT public authorities*, August 2018.
140	Royal Commission and Board of Inquiry into the Protection and Detention of Children in the Northern Territory, *Report of the Royal Commission and Board of Inquiry into the protection and detention of children in the Northern Territory*, November 2017.
141	Northern Territory Ombudsman, *Women in prison II – Alice Springs Women's Correctional Facility*, Investigation report vol 1 of 2, May 2017.
142	Alan Ferris, Keith Hamburger, John Hocken, Lee Downes, Therese Ellis-Smith & Neil McAllister, *A safer Northern Territory through correctional interventions*, Report of the Review of the Northern Territory Department of Correctional Services, July 2016.
143	Northern Territory Law Reform Committee, *Report on the interaction between people with mental health issues and the criminal justice system*, Report no 42, May 2016.
144	Select Committee on Action to Prevent Foetal Alcohol Spectrum Disorder, Legislative Assembly of the Northern Territory, *The preventable disability*, Inquiry report, February 2015.
145	Board of Inquiry into the Child Protection System in the Northern Territory, *Growing them strong, together: Promoting the safety and wellbeing of the Northern Territory's children*, Final report vol 1, 2010.

Report no	Report citation
146	Northern Territory Ombudsman, *Women in prison Northern Territory*: Report of the investigation into complaints from women prisoners at Darwin Correctional Centre 2008, April 2008.
147	Northern Territory Board of Inquiry into the Protection of Aboriginal Children from Sexual Abuse, *Ampe akelyernemane meke mekarle 'Little children are sacred'*, Inquiry final report, April 2007.

Queensland

Report no	Report citation
148	Queensland Productivity Commission, *Inquiry into imprisonment and recidivism*, August 2019.
149	Queensland Anti-Discrimination Commission, *Women in prison 2019: A human rights consultation report,* 2019.
150	Queensland Ombudsman, *The Forensic Disability Service report: An investigation into the detention of people at the Forensic Disability Service*, August 2019.
151	Queensland Government Department of Communities, Disability Services and Seniors, *Section 157: Review of the operation of the Forensic Disability Act 2011*, Final report, October 2018.
152	Bob Atkinson, *Report on youth justice*, Report prepared for the Queensland Minister for Child Safety, Youth and Women and Minister for Prevention of Domestic and Family Violence, version 2, June 2018.
153	Queensland Law Reform Commission, *Review of termination of pregnancy laws*, Report no 76, June 2018.
154	Dylan Kerr, Ellen Limerick, Lauren Causer & Taylor Thomas, *Declared unfit to plead*, Research report prepared for the Queensland Anti-Discrimination Commission, Queensland Government Office of the Public Advocate and Queensland Government Office of the Public Guardian, April 2018.
155	Deloitte Access Economics, *Review of education for students with disability in Queensland state schools*, Report commissioned by the Queensland Government Department of Education and Training, February 2017.

Report no	Report citation
156	Office of the Public Advocate for Queensland, *Upholding the right to life and health: A review of the deaths in care of people with disability in Queensland*, Systemic advocacy report, February 2016.
157	Queensland Advocacy Incorporated, *dis-Abled justice: Reforms to justice for persons with disability in Queensland*, May 2015.
158	Special Taskforce on Domestic and Family Violence in Queensland, *Not now, not ever: Putting an end to domestic and family violence in Queensland*, Final report to the Premier of Queensland, February 2015.
159	Queensland Child Protection Commission of Inquiry, *Taking responsibility: A roadmap for Queensland child protection*, Final report to the Premier of Queensland, June 2013.
160	Queensland Law Reform Commission, *A review of Queensland's guardianship laws*, Report no 67, vol 1, September 2010.
161	Phillip French, *Disabled justice: The barriers to justice for persons with disability in Queensland*, Report prepared for Queensland Advocacy Incorporated, May 2007.
162	The Hon William Carter QC, the Directors-General of Communities and Disability Services Queensland and the Queensland Government Department of Housing, *Challenging behaviour and disability: A targeted response*, Report to the Hon Warren Pitt MP, Minister for Communities, Disability Services and Seniors, July 2006.

South Australia

Report no	Report citation
163	Safeguarding Task Force, *Interim report*, Commissioned by the South Australian Minister for Human Services, June 2020.
164	Social Development Committee, Parliament of South Australia, *Mental health services and the NDIS: Inquiry into the provision of services for people with mental Illness in the transition to the National Disability Insurance Scheme*, Report no 42, December 2019.
165	JFA Purple Orange, *South Australia's first disability inclusion plan 2019–2023*, Community consultation: Summary report, July 2019.
166	Select Committee on Access to the South Australian Education System for Students with Disability, Parliament of South Australia, *Access to the South Australian education system for students with a disability*, Parliamentary Paper no 312, 30 May 2017.
167	Child Protection Systems Royal Commission, *The life they deserve*: Child Protection Systems Royal Commission Report, Summary and report, vol 1, August 2016.
168	Social Development Committee, Parliament of South Australia, *Inquiry into comorbidity*, Report no 38, September 2015.
169	South Australian Government Social Inclusion Board, *Strong voices: A blueprint to enhance life and claim the rights of people with disability in South Australia (2012–2020)*, October 2011.
170	Statutory Authorities Review Committee, Legislative Council of Parliament of South Australia, *Inquiry into the Office of the Public Trustee*, Report no 51, December 2009.

Tasmania

Report no	Report citation
171	Tasmania Law Reform Institute, *Review of the defence of insanity in s 16 of the Criminal Code and fitness to plead*, Final report no 28, December 2019.
172	KPMG, *Development of a needs-based funding model for students with disability*, Final report commissioned by the Tasmanian Government Department of Education, February 2019.
173	Tasmania Law Reform Institute, *Review of the Guardianship and Administration Act 1995 (Tas)*, Final report no 26, December 2018.
174	Tasmanian Government Department of Health and Human Services, *Review of the Disability Services Act 2011*, June 2018.
175	Tasmanian Law Reform Institute, *Facilitating Equal Access to Justice: An Intermediary/Communication Assistant Scheme for Tasmania?*, Final report No 23, January 2018.
176	Tasmanian Government Department of Premier and Cabinet, *Accessible Island: Tasmania's Disability Framework for Action 2018-2021*, 2018.
177	Tasmanian Government Department of Health and Human Services, *Autism advisory panel final report*, 2018.
178	Equal Opportunity Tasmania, *Disability framework for action 2018–2020*, Submission by the Tasmanian Anti-Discrimination Commissioner, June 2017.
179	Tasmanian Government Minister for Education and Training, *Improved support for students with disability*, Ministerial Taskforce Report, August 2015.
180	Joint Standing Committee on Community Development, Parliament of Tasmania, *Report on the provision of assistive technology and equipment for people with disabilities*, November 2008.

Victoria

Report no	Report citation
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189	Victorian Mental Health Complaints Commissioner, *The right to be safe: Ensuring sexual safety in acute mental health inpatient units*, Project report, March 2018.
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193	Victorian Ombudsman, *Investigation into Victorian government school expulsions*, August 2017.
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246	United Kingdom Equality and Human Rights Commission, *Hidden in plain sight: Inquiry into disability-related harassment*, September 2011.

Appendix C: Key activities and publications to date

This Appendix lists the Royal Commission's key activities and publications from 5 April 2019 to 31 July 2020. It is not a comprehensive list of all Royal Commission activities.

The Royal Commission suspended all activities involving gatherings of people or close contact between individuals on 16 March 2020 due to the COVID-19 pandemic and concerns for the health and safety of people with disability, the community at large and members of staff.

Despite this, the Royal Commission's work continued during the pandemic. We received submissions, published issues papers, progressed our research and policy work and prepared for public hearings. We also continued to engage with people with disability, their supporters and stakeholders online and by telephone and mail.

The Royal Commission resumed public activities in August 2020 and carefully adheres to all official advice regarding physical distancing and other public health measures.

Public hearings

This list includes public hearings held up until 31 July 2020. Full transcripts of public hearings are available on the 'Public hearings' page of the Royal Commission website.[1] Further planned public hearings for the remainder of 2020 are listed in Chapter 7, 'Public hearings'.

Hearing title	Location	Date
Public hearing 1: Ceremonial opening sitting	Brisbane, Qld	16 September 2019
Public hearing 2: Inclusive education in Queensland – preliminary inquiry	Townsville, Qld	4–7 November 2019
Public hearing 3: The experience of living in a group home for people with disability	Melbourne, Vic	2–6 December 2019
Public hearing 4: Health care and services for people with cognitive disability	Sydney, NSW	18–28 February 2020

Private sessions

Location	Number of sessions	Date
Melbourne, Vic	5	February 2020
Teleconference/videoconference	12	June–July 2020

Workshops

Theme	Location	Date
Advocacy workshop	Melbourne, Vic	18 June 2019
Legal workshop	Sydney, NSW	1 July 2019
Legal workshop	Brisbane, Qld	3 July 2019
Legal workshop	Melbourne, Vic	9 July 2019
Disability service providers workshop	Melbourne, Vic	18 July 2019
First Nations people and communities workshop	Sydney, NSW	6 August 2019
First Nations people and communities workshop	Darwin, NT	15 August 2019
Justice workshop	Melbourne, Vic	2 September 2019
Education and learning workshop	Melbourne, Vic	3 October 2019

Community engagement

Community forums

Location	Date
Townsville, Qld	9 September 2019
Adelaide, SA (Session 1)	12 November 2019
Adelaide, SA (Session 2)	12 November 2019
Gawler, SA	14 November 2019
Hobart, Tas (Session 1)	26 November 2019
Hobart, Tas (Session 2)	26 November 2019
Logan, Qld	4 February 2020
Ipswich, Qld	5 February 2020

Engagement with First Nations people and communities

Engagement	Location	Date
First Nations engagement	Bwgcolman (Palm Island), Qld	8 November 2019
First Nations engagement	Beaudesert, Qld	14 January 2020
First Nations engagement	Gold Coast, Qld	15 January 2020
First Nations engagement	Logan, Qld	3 February 2020
First Nations engagement	Ipswich, Qld	4 February 2020
First Nations engagement	Brisbane, Qld	6 February 2020
First Nations engagement	Darwin, NT	10 February 2020
First Nations engagement	Darwin, NT	11 February 2020

Engagement	Location	Date
First Nations engagement	Papunya, NT	13 February 2020
First Nations engagement	Alice Springs, NT	12–14 February 2020
Meeting of the First Nations Peoples Strategic Advisory Group	Brisbane, Qld	2 March 2020
First Nations engagement	Cherbourg, Qld	5 March 2020
First Nations engagement	Toowoomba, Qld	6 March 2020
First Nations engagement	Canberra, ACT	23 March 2020
First Nations engagement	Teleconference/videoconference	14 April 2020
First Nations engagement	Teleconference/videoconference, SA	30 April 2020
First Nations engagement	Teleconference/videoconference	19 May 2020
First Nations engagement	Teleconference/videoconference	11 June 2020
First Nations engagement	Teleconference/videoconference, SA	18 June 2020
First Nations engagement	Teleconference/videoconference, WA	18 June 2020
Meeting of the First Nations Peoples Strategic Advisory Group	Teleconference/videoconference	19 June 2020
First Nations engagement	Teleconference/videoconference, WA	19 June 2020
First Nations engagement	Teleconference/videoconference, WA	24 June 2020
Meeting of the First Nations Peoples Strategic Advisory Group	Teleconference/videoconference	21 July 2020
First Nations Engagement	Teleconference/videoconference	22 July 2020
First Nations Engagement	Teleconference/videoconference	23 July 2020

Engagement with culturally and linguistically diverse communities

Engagement	Location	Date
Community engagement	Hobart, Tas	27 November 2019
Community engagement	Melbourne, Vic	4 December 2019
Community engagement	Melbourne, Vic	5 December 2019
Community engagement	Melbourne, Vic	6 December 2019
Community engagement	Logan, Qld	19 December 2019
Community engagement	Melbourne, Vic	14 January 2020
Community engagement	Brisbane, Qld	14 January 2020
Community engagement	Brisbane, Qld	15 January 2020
Community engagement	Logan, Qld	20 January 2020
Community engagement	Brisbane, Qld	6 February 2020
Community engagement	Logan, Qld	20 February 2020
Community engagement	Melbourne, Vic	24 February 2020
Community engagement	Perth, WA	2 March 2020
Community engagement	Logan, Qld	3 March 2020
Community engagement	Melbourne, Vic	24 March 2020
Community engagement	Teleconference/ videoconference	22 April 2020
Culturally and linguistically diverse national roundtable	Teleconference/ videoconference	26 May 2020
Presentation	Teleconference/ videoconference	25 June 2020
Presentation	Brisbane, Qld	14 July 2020
Presentation	Teleconference/ videoconference	24 July 2020

Engagement with disability peak bodies and advocates

Engagement	Location	Date
Presentation	Brisbane, Qld	30 October 2019
Presentation	Adelaide, SA	6 November 2019
Presentation	Perth, WA	7 November 2019
Presentation	Hobart, Tas	21 November 2019
Presentation	Sydney, NSW	22 November 2019
Presentation	Melbourne, Vic	29 November 2019
Engagements	Melbourne, Vic	2–6 November 2019
Presentation	Brisbane, Qld	10 December 2019
Presentation	Sydney, NSW	12 December 2019
Engagements	NSW	December 2019–February 2020
Presentation	Sydney, NSW	28 January 2020
Engagements	Tas	January 2020
Presentation	Brisbane, Qld	12 March 2020
Engagements	Teleconference/videoconference	20 May 2020
Engagements	Teleconference/videoconference	17 June 2020
Engagements	Brisbane, Qld	29 July 2020

Publications

Issues papers

All issues papers are available on the 'Issues papers' page of the Royal Commission website.[2]

Issues paper title	Publication date
Education and learning issues paper	30 October 2019
Group homes issues paper	28 November 2019
Health care for people with cognitive disability issues paper	16 December 2019
Criminal justice system issues paper	14 January 2020
Emergency planning and response issues paper	15 April 2020
Rights and attitudes issues paper	28 April 2020
Employment issues paper	12 May 2020
Restrictive practices issues paper	26 May 2020
The experience of First Nations People with Disability in Australia issues paper	9 June 2020

Other key publications

These and other publications are available in the 'Document library' on the Royal Commission website.[3]

Publication	Publication date
Accessibility and Inclusion Strategy	19 August 2019
First Progress Report	20 December 2019
Statement of concern – The response to the COVID-19 pandemic for people with disability	26 March 2020
First Nations Engagement Principles	19 June 2020
Second Progress Report	11 August 2020

Endnotes

1 ‘Our public hearings’, *Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability*. <https://disability.royalcommission.gov.au/public-hearings/our-public-hearings>
2 ‘Issues papers’, *Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability*. <https://disability.royalcommission.gov.au/policy-and-research/issues-papers>
3 ‘Document Library’, *Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability*. <https://disability.royalcommission.gov.au/document-library>

Appendix D: A brief overview of the National Disability Insurance Scheme

Introduction

The National Disability Insurance Scheme (NDIS) is one of the most significant changes to social policy in Australia. Its scale and impact has been compared to Medicare, Australia's universal health system, and to compulsory superannuation.[1] It is the first nationally consistent system of support for people with permanent disability. The NDIS is intended to replace most of the specialist disability support systems previously provided under the National Disability Agreement (NDA), the agreement between the Australian, state and territory governments relating to services for people with disability.[2]

The Royal Commission's terms of reference specifically refer to the NDIS.[3] The Royal Commission has yet to start our substantive inquiries into the safety and quality of services under the NDIS and NDIS Quality and Safeguarding Framework. Nevertheless, given the significance of the NDIS model to many areas of disability services, including homes and living and employment, this appendix gives a short overview of the development of the scheme and its original intent (noting that this may differ from how the NDIS currently operates in practice).

The development of the NDIS

Pre-NDIS approaches

Australia's journey to the NDIS has taken more than 40 years. The concept of a national injury compensation scheme similar to that introduced in New Zealand in 1972 following the 1967 Woodhouse Committee Report[4] was first discussed by the Whitlam government in the early 1970s.[5] The NDIS was raised at the Australia 2020 Summit (held in April 2008) and referred by the Rudd government for inquiry to the Productivity Commission in February 2010, which recommended the scheme's implementation in its report of August 2011.[6] The Gillard government legislated the NDIS in 2013.[7] Along the way the design of the NDIS was also shaped by broader rights issues and the evolution of community attitudes to disability long fought for by advocates in Australia.

Before the NDIS, state and territory governments funded non-profit service providers directly, through contracted lump-sum payments. This was the 'block funding model' for individual services, group home and adult day program places.[8] The Australian Government also funded Australian Disability Enterprises (ADEs) and Disability Employment Services (DES) to provide employment opportunities.[9] Under these models, people with disability were often allocated services based on their location or availability, rather than their individual needs or preferences.

Many social and political factors led to the NDIS in its current form. Some of the most influential contributions were the *Shut out report*,[10] the strategy behind and effectiveness of the Every Australian Counts campaign,[11] and the unequivocal support of the Productivity Commission for such a scheme in its 2011 report, *Disability care and support*.[12]

The 2011 Productivity Commission report

The proposals for the NDIS were developed in response to the Productivity Commission's *Disability care and support* report.[13] This report remains the blueprint for the NDIS, although the scheme has some key differences from the design advanced in it. The report described existing systems of care and support for people with disability in Australia as 'underfunded, unfair, fragmented, and inefficient', and offered 'little choice and no certainty of access to appropriate supports'.[14] The Productivity Commission recommended the establishment of a scheme to 'provide insurance cover for all Australians in the event of significant disability'.[15]

The report recommended the scheme should have a cohesive and comprehensive framework for providing supports to people with disability, with consistent eligibility criteria that would apply Australia-wide.[16] Rather than offering income support, the NDIS would fund the provision of lifelong supports and services, tailored to the individual needs of each participant. The report noted that a person would also be able to take their funding with them across state and territory borders.[17]

The establishment of the NDIS

The NDIS was developed in line with these recommendations through a cooperative process between the Australian, state and territory governments.[18] This culminated in the passage of the *National Disability Insurance Scheme Act 2013* (Cth) (*NDIS Act*), which established an Australia-wide scheme for the delivery of supports and services to eligible people with disability.

The NDIS represented a fundamental departure from the previous state and territory-based systems in favour of a model that:[19]

- delivers individually tailored supports and services to people with disability
- adopts a consumer-driven approach to the delivery of care, where participants directly purchase the services they need
- manages the long-term costs and financial risks of the NDIS in line with insurance principles.

The NDIS was progressively rolled out from 2016, following a trial period, replacing nine diverse Australian state and territory systems of funding for supports and services for people with disability. It is now in full operation in all jurisdictions except Western Australia. It will commence operating in Western Australia on 1 December 2020.[20]

The purpose of the NDIS

The *NDIS Act* establishes the scheme and sets out the framework under which eligible people with disability receive funding for disability supports and services. It was estimated that around 460,000 people would receive direct funding once implementation was complete.[21] This is around 10 per cent of people with disability in Australia and roughly double the estimated number of people supported under previous government systems.[22]

Among other things, the *NDIS Act* sets out:

- the process by which a person with disability can become a participant in the NDIS
- the principles for the preparation of individual 'plans' setting out the supports and services that will be provided to each participant and funded under the NDIS
- the oversight, regulation and quality assurance of provider supports and services to participants.

The *NDIS Act* establishes two key bodies that are responsible for the delivery and oversight of the NDIS: the National Disability Insurance Agency (NDIA)[23] and the NDIS Quality and Safeguards Commission (NDIS Commission).[24] Broadly, the NDIA administers the scheme and the entitlements and plans of participants, while the NDIS Commission is responsible for developing a nationally consistent approach to managing quality and safeguards and promoting and securing compliance with the *NDIS Act*, among other functions.[25] The NDIS Commission is also responsible for overseeing the quality and safety of NDIS-funded services.

The *NDIS Act* is supplemented by various rules,[26] guidelines and other legislative instruments. The legislation also interacts with other areas of law – for example, the state and territory regulation of the use of restrictive practices and the screening of workers in the disability sector.

The NDIS operates alongside a range of mainstream service systems, such as health, education and justice. While the *NDIS Act* expressly acknowledges the need for interaction between the provision of mainstream services and the provision of supports under the NDIS,[27] the scheme does not replace services that any citizen could expect, such as public transport and hospital services.

Objects of the NDIS

Section 3 of the *NDIS Act* sets out the objects of the NDIS. These include:

- supporting the independence and social and economic participation of people with disability[28]
- providing reasonable and necessary supports, including early intervention supports, for participants in the NDIS[29]
- enabling people with disability to exercise choice and control in the pursuit of their goals and the planning and delivery of their supports[30]
- facilitating the development of a nationally consistent approach to access to, and planning and funding of, supports for people with disability[31]
- protecting and preventing people with disability from experiencing harm arising from poor quality or unsafe supports or services provided under the NDIS.[32]

Section 3 also requires consideration of other matters in pursuing these objects, such as the financial sustainability of the NDIS.[33]

The administration of the *NDIS Act* is governed by the rights-focused guiding principles set out in section 4 of the Act. These principles aim to ensure that people with disability can participate in society,[34] exercise choice in the pursuit of their goals[35] and realise their rights on an equal basis with other members of the community.[36]

An insurance model

Although the NDIS is described as an 'insurance' scheme, it does not involve insurance in the traditional sense. Rather, it is characterised as a form of community-wide, publicly funded insurance against the cost of providing long-term supports for people with disability.[37]

The NDIS also adopts an insurance approach to managing its long-term financial sustainability. Under this approach, the scheme's funding needs are calculated by reference to the estimated expenditure required over each participant's lifetime, and the scheme is managed accordingly.[38] The *NDIS Act* provides for regular actuarial assessment of the scheme's likely future expenditure and risks to its financial sustainability.[39] The scheme closely tracks the outcomes for participants year to year and uses this data to adjust individual plans and the scheme as a whole.[40]

The insurance model aims to ensure that the funding available to participants does not fluctuate from year to year depending on government budget cycles and competing economic demands.[41] Of critical importance, this model is also intended to enable the NDIS to make upfront investments in improving participants' independence and capacity so as to achieve longer-term improvements in outcomes for individuals and savings for Australia.[42] For example, a participant may be supported to achieve a goal of moving into their own home.

Individualisation and consumer choice

The NDIS is designed to provide supports and services to people with disability that are tailored to their specific needs and circumstances. In particular, the aim is for each participant in the NDIS to have an individualised plan, which sets out the person's goals, details of their life and living arrangements, with services chosen by the participant that they consider will best meet their individual needs and preferences.[43] To enable participants to have real choice, service offerings must reflect the diversity of people with disability. People may have specific needs, priorities and perspectives based on their personal circumstances, including the type and level of support required, education, gender, age, sexuality, and ethnic or cultural background.[44]

The NDIS also recognises the right of people with disability to control all aspects of their daily lives, in a way that was not possible under previous systems. A key object of the *NDIS Act* is that participants can choose who will provide them with supports and services and the key object of the NDIS is therefore that a participant will have 'choice and control'.[45] The intention is that as the range of responsive service offerings develops, participants are free, at least in theory, to switch between and choose different NDIS providers to suit their needs. Except in certain circumstances, participants also have the option of managing their own funding under their plan.[46] Instead of funding being paid directly by government(s) to a specified provider, the person receives the funds themselves via the NDIS and purchases supports directly.

The Productivity Commission suggested that locating choice and control with participants is also intended to stimulate innovation in services.[47] It represents a major shift from earlier models, under which governments contracted directly with providers, determined the services to be procured and allocated clients to providers in bulk. In light of the significant implications of this transition for participants and providers, and the need for rapid growth in supply of services as the NDIS is implemented, the NDIA has assumed a 'market stewardship' role.[48] It regulates service provision more closely than intended once the Scheme is mature.[49]

Main features of the NDIS

Eligibility requirements

The NDIS has several key eligibility requirements for participants. Under the *NDIS Act*, a person must meet:

- the age requirement – the person was aged under 65 when the access request was made (but may then remain in the scheme on reaching 65).[50]
- the residence requirement – the person resides in Australia and is a citizen or the holder of a permanent visa or protected special category visa.[51] A protected special category visa is a temporary visa granted primarily to New Zealand citizens subject to satisfying certain character and health requirements.[52]
- the disability requirement – the person has a disability that is attributable to one or more 'intellectual, cognitive, neurological, sensory or physical impairments or to one or more impairments attributable to a psychiatric condition'.[53] Further, that the impairment is permanent, results in substantially reduced functional capacity (whereby the person usually requires the help of another person or assistive device to perform daily living)

and affects the capacity for social and economic participation.[54] Alternatively, a person may be eligible under the early intervention requirements.[55] The Productivity Commission report has indicated that early intervention may reduce future needs for supports in relation to a person's disability.[56]

A decision that a person does not meet the eligibility requirements is a 'reviewable decision' under section 99 of the *NDIS Act.* The rejection of a request to become a participant does not prevent the person from reapplying.[57] However, a person may not make further requests until any internal review of the 'reviewable decision', or subsequent merits review by the Administrative Appeals Tribunal, is finalised.[58]

Participant plans

Once a person has met the eligibility requirements and become a participant in the NDIS, they will be helped to develop a personal plan setting out their goals and aspirations and detailing the supports that will be funded for them. Plans are reviewed at intervals.[59]

Section 31 of the *NDIS Act* sets out the principles relating to the preparation, management, review and replacement of a participant's plan. Specifically, a participant's individual plan should, so far as is reasonably practicable:

- be individualised[60]
- be directed by the participant[61]
- consider and respect the role of family, carers and other persons who are significant in the life of the participant[62]
- strengthen and build capacity of families and carers to support the participant in adult life[63]
- support communities to respond to the individual goals and needs of participants[64]
- be underpinned by the right of the participant to exercise control over his or her own life[65]
- advance the inclusion and participation in the community of the participant with the aim of achieving their individual aspirations[66]
- maximise the choice and independence of the participant[67]
- facilitate tailored and flexible responses to the individual goals and needs of the participant[68]
- provide the context for the provision of disability services to the participant and, where appropriate, coordinate the delivery of disability services where there is more than one disability service provider.[69]

A participant's plan must set out a range of matters, including:[70]

- a statement of the participant's goals and aspirations, and the environmental and personal context in which they live
- a 'statement of participant supports'.

The 'statement of participant supports' must identify:[71]

- the 'general supports' to be provided
- the 'reasonable and necessary supports' that will be funded under the NDIS
- who will manage the funding for supports under the plan.

Reasonable and necessary supports

While the *NDIS Act* does not define the concept of 'reasonable and necessary supports', the legislation does provide that 'reasonable and necessary supports' should:[72]

- support people with disability to pursue their goals and maximise their independence
- support people with disability to live independently and be included in the community as fully participating citizens
- develop and support the capacity of people with disability to undertake activities that enable them to participate in the community and in employment.

These supports can take many forms, such as:[73]

- mobility equipment
- home or vehicle modifications
- assistance with daily personal activities
- transport to enable participation in community, social, economic and daily life activities.

In determining the 'reasonable and necessary supports' that should be funded for the participant, the NDIA must be satisfied of a range of matters, including that:

- the support will assist the participant to pursue the goals, objectives and aspirations included in the participant's statement of goals and aspirations[74]
- the support will facilitate the participant's social and economic participation[75]
- the support represents value for money[76]
- the support will be, or is likely to be, effective and beneficial for the participant, having regard to current good practice and evidence[77]
- 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[78]
- the supports are most appropriately funded through the NDIS (and not other general service systems or supports).[79]

The NDIS Quality and Safeguards Commission

The NDIS Commission is established under the *NDIS Act* and consists of the Quality and Safeguards Commissioner (the NDIS Commissioner) and the staff of the NDIS Commission.[80]

The NDIS Commissioner is responsible for, among other things:

- upholding the rights of, and promoting the health, safety and wellbeing of, people with disability receiving supports or services
- developing a nationally consistent approach to managing quality and safeguards for people with disability receiving supports or services, including under the NDIS.[81]

The NDIS Commission is accountable for specific areas that relate to the quality and safeguarding of the NDIS, including:[82]

- responding to concerns, complaints and reportable incidents, including abuse and neglect of NDIS participants
- promoting the NDIS principles of choice and control, and working to empower participants to exercise their rights to access quality services as informed, protected consumers
- requiring NDIS providers to uphold participants' rights to be free from harm
- registering and regulating NDIS providers, and overseeing
    - the *National Disability Insurance Scheme (Code of Conduct) Rules 2018* (Cth) (*NDIS Code of Conduct Rules*) and
    - the *National Disability Insurance Scheme (Provider Registration and Practice Standards) Rules 2018* (Cth) (*NDIS Practice Standards Rules*)[83]
- monitoring compliance against the *NDIS Code of Conduct Rules* and the *NDIS Practice Standards Rules*, including carrying out investigations and taking enforcement action
- monitoring the use of restrictive practices within the NDIS with the aim of reducing and eliminating them.

The NDIS Commission also manages the implementation of the NDIS Quality and Safeguarding Framework, which is a national approach to quality and safeguarding for NDIS participants.

The framework covers:[84]

- replacing existing state and territory quality and safeguarding measures
- empowering and supporting NDIS participants
- addressing systemic issues
- providing consistency
- enabling effective monitoring and responses.

The framework principles uphold the rights of people with disability and aim to ensure that they are provided with the opportunity to exercise choice and control.[85] The framework is underpinned by legal and policy provisions, such as the United Nations *Convention on the Rights of Persons with Disabilities*, the Australian Government National Disability Strategy 2010–2020 and the *NDIS Act.[86]* (For more on the National Disability Strategy see Chapter 1, 'Why this Royal Commission is needed'.)

Regulation of providers

Under the framework, an NDIS provider's registration is subject to a range of conditions.[87] A provider who breaches a condition of registration may be liable to pay a civil penalty.[88]

The *NDIS Act* sets out conditions that apply to the registration of all NDIS providers, including the requirements to:[89]

- comply with all applicable requirements imposed by a law of the Australian Government or the state or territory government in which the provider operates
- comply with the *NDIS Code of Conduct Rules*
- comply with the *NDIS Practice Standards Rules*
- implement and maintain complaints management and incident reporting systems that meet the requirements of the *NDIS Act.*[90]

The NDIS Commissioner may impose further conditions on a provider's registration.[91] Registered providers are also subject to a range of price controls and other regulations such as specifications of standards about services, for example, Specialist Disability Accommodation.[92] These regulations are imposed by the NDIA as part of its market stewardship function.[93]

Previous reports on the NDIS

The NDIS has been the subject of many extensive reports. The Royal Commission will consider and build on this work where relevant to our terms of reference, but our inquiry is not a review of the NDIS.

Some of the more significant reports on proposed schemes and the NDIS include:

- the 2011 Productivity Commission report, *Disability care and support*, which remains the blueprint for the NDIS[94]
- the 2017 Productivity Commission report, *National Disability Insurance Scheme (NDIS) costs*, which concluded that, if implemented well, the NDIS would substantially improve the wellbeing of people with disability and Australians more generally[95]
- regular inquiries conducted by the Australian Parliament's Joint Standing Committee on the National Disability Insurance Scheme[96]
- the 2019 review of the *NDIS Act* and the NDIS participant guarantee by Mr David Tune AO PSM.[97]

The Royal Commission will inquire into the changes that should be made to the NDIS to ensure that participants, so far as possible, are not subject to violence, abuse, neglect or exploitation.

NDIS participant numbers

NDIS participation has not yet reached the numbers estimated under the bilateral agreements between the Australian, state and territory governments for its implementation.[98] At 31 March 2020, the NDIS had 364,879 active participants nationally, broken down by states and territories as shown in Table D.1.[99]

Table D.1: NDIS plan approvals by state and territory at 31 March 2020

State/ territory	All plans approved (excl. ECEI)	ECEI	All plans approved (incl. ECEI)	Total bilateral estimates	Comparison (for all plan approvals incl. ECEI) with bilateral estimates
NSW	124,611	2299	126,910	141,957	89%
Vic	100,840	1265	102,105	105,324	97%
Qld	67,867	1238	69,105	91,217	76%
WA	27,477	102	27,579	34,550	80%
SA	34,792	256	35,048	32,284	109%
Tas	8426	211	8637	10,587	82%
ACT	8694	110	8804	5075	173%
NT	3204	60	3264	6142	53%
Total	**375,911**	**5541**	**381,452**	**427,136**	**89%**

Note: Early Childhood Early Intervention (ECEI) is the approach for children under 7 with a developmental delay or disability.

Source: National Disability Insurance Scheme (2020).

Despite the development and release of specific strategies by the NDIA, such as the Aboriginal and Torres Strait Islander Engagement Strategy 2017 and the Cultural and Linguistic Diversity Strategy 2018, the engagement of First Nations people and culturally and linguistically diverse communities remains below estimates.[100]

At 31 March 2020, there were 22,749 First Nations participants in the NDIS, which is 6.2 per cent of all active participants in the scheme.[101] Around 45,000 First Nations adults had a 'profound or severe' disability, or around 1 in 10 First Nations adults.[102]

The Royal Commission has been told by First Nations people of a number of reasons why they may not be NDIS participants, even though they may be eligible. These include challenges related to the access process, stigmatisation and social marginalisation in their communities and limited availability of services in some locations.[103] Previous reports on the NDIS have also noted continued underperformance in its operation and engagement with respect to First Nations people (see Chapter 18, 'First Nations people with disability', for further details). Table D.2 shows the participation of First Nations people in the NDIS by age group.[104]

Table D.2: Participation of First Nations people in the NDIS by age group

Age group	NDIS actual	NDIS expected
Overall	6%	7%
0–14 years	7%	8%
15–34 years	6%	7%
35–54 years	5%	6%
55+ years	3%	3%

Source: National Disability Insurance Scheme (2019).

Culturally and linguistically diverse people are also under-represented as NDIS participants. Estimates in the NDIA Cultural and Linguistic Diversity Strategy 2018 anticipated that 20 per cent of NDIS participants would be people from culturally and linguistically diverse backgrounds.[105] There is no broadly agreed definition of 'cultural and linguistic diversity'. The number of people with disability who are culturally and linguistically diverse may be under-represented in the data below because country of birth and the language spoken at home does not show whether someone identifies as culturally or linguistically diverse. In 2018, there were:

- around 643,000 people with disability who were born outside of Australia in a country that was not a 'main English-speaking country'.[106] This is almost 15 per cent of all people with disability.
- around 345,500 people with disability who spoke a language other than English at home.[107] This is around 8 per cent of all people with disability.
- around 136,500 people with disability who spoke English 'not well' or 'not at all'.[108] This is around 3 per cent of all people with disability.

At 30 June 2019, 8 per cent of NDIS participants were from this group.[109] Table D.3 lists the proportion of culturally and linguistically diverse NDIS participants by age group.[110]

Table D.3: Participation of culturally and linguistically diverse people in the NDIS by age group

Age group	NDIS actual	NDIS expected
0–14 years	7%	14%
15–24 years	6%	15%
25–34 years	7%	23%
35–44 years	10%	27%
45–54 years	10%	30%
55–64 years	12%	32%
Overall	**8%**	**21%**

Source: National Disability Insurance Scheme (2019).

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Acronyms and abbreviations

List of acronyms and abbreviations used in this report

Acronym/ Abbreviation	Expansion
ACT	Australian Capital Territory
ADA Australia	Aged and Disability Advocacy Australia
ADACAS	ACT Disability, Aged and Carer Advocacy Service
ADEC	Action on Disability within Ethnic Communities
ADEs	Australian Disability Enterprises
AEST	Australian Eastern Standard Time
Aged Care Royal Commission	Royal Commission into Aged Care Quality and Safety
AGOP	Australian Government Plan to Improve Outcomes for Aboriginal and Torres Strait Islander People with Disability
AHRC	Australian Human Rights Commission
AIHW	Australian Institute of Health and Welfare
AMIDA	Action for More Independence and Dignity in Accommodation
AMSANT	Aboriginal Medical Services Alliance Northern Territory
APS	Australian Public Service
CHAP	Comprehensive Health Assessment Program
CIMS	Client Incident Management System
COAG	Council of Australian Governments
CORAS	Colac Otway Region Advocacy Service
COVID-19	Corona Virus Disease, discovered in 2019. The strain of coronavirus which causes the disease is severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2).
CRC	*Convention on the Rights of the Child*
CRPD	*Convention on the Rights of Persons with Disabilities*
CRPD Committee	Committee on the Rights of Persons with Disabilities
CRU	community residential unit
Cth	Commonwealth
DACSSA	Disability Advocacy and Complaints Service of South Australia Inc
DAS	Disability Advocacy Service Inc

Acronym/ Abbreviation	Expansion
DDA	*Disability Discrimination Act 1992* (Cth)
DES	Disability Employment Services
DHHS	Department of Health and Human Services Victoria
DSEG	Disability Strategic Engagement Group
DSP	Disability Support Pension
DSS	Department of Social Services
EAP	Education Adjustment Program
ECEI	Early Childhood Early Intervention
FASD	fetal alcohol spectrum disorder
FND	functional neurological disorder
FNPSAG	First Nations Peoples Strategic Advisory Group
FPDN	First Peoples Disability Network Australia
GDA	Gippsland Disability Advocacy
GP	General Practitioner
HRW	Human Rights Watch
IAP2	International Association for Public Participation Australasia
LGBTIQ+	lesbian, gay, bisexual, transgender, intersex, queer and questioning
LHD	Local Health District
MBBS	Bachelor of Medicine and Bachelor of Surgery
MBS	Medicare Benefits Schedule
MD	Doctor of Medicine
MDAA	Multicultural Disability Advocacy Association of NSW
MEDA	Melbourne East Disability Advocacy
Midlas	Midland Information, Debt and Legal Advocacy Service Inc
National Roundtable	National Roundtable on the Mental Health of People with Intellectual Disability
NATSILS	National Aboriginal and Torres Strait Islander Legal Services
NATSISS	National Aboriginal and Torres Strait Islander Social Survey
NCCD	Nationally Consistent Collection of Data on School Students with Disability

Acronym/ Abbreviation	Expansion
NDA	National Disability Agreement
NDAP	National Disability Advocacy Program
NDIA	National Disability Insurance Agency
NDIS	National Disability Insurance Scheme
NDIS Commission	NDIS Quality and Safeguards Commission
NDIS Commissioner	NDIS Quality and Safeguards Commissioner
NDS	National Disability Strategy 2010-2020
NHLF	National Health Leadership Forum
NPY	Ngaanyatjarra Pitjantjatjara Yankunytjatjara
NPY Women’s Council	Ngaanyatjarra Pitjantjatjara Yankunytjatjara Women’s Council
NSW	New South Wales
NT	Northern Territory
OECD	Organisation for Economic Co-operation and Development
OSA	Office of the Solicitor Assisting
OSCE	Objective Structured Clinical Exam
PHN	Primary Health Network
PTSD	post-traumatic stress disorder
PWDA	People With Disability Australia
PWDWA	People With Disabilities WA
QAIHC	Queensland Aboriginal and Islander Health Council
QHRC	Queensland Human Rights Commission
Qld	Queensland
RDAS	Regional Disability Advocacy Service
RIAC	Rights Information and Advocacy Centre
Royal Commission	Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability
SA	South Australia
SDA	Specialist Disability Accommodation
SIL	Supported Independent Living
Speak Out	Speak Out Association of Tasmania

Acronym/ Abbreviation	Expansion
SUFY	Speaking Up For You
SWAA	Southwest Advocacy Association
Tas	Tasmania
The Scheme	National Disability Insurance Scheme
TIS	Translating and Interpreting Service
Uluru Statement	Uluru Statement From the Heart
UNDRIP	*United Nations Declaration on the Rights of Indigenous Peoples*
VALID	Victorian Advocacy League for Individuals with Disability
Vic	Victoria
VicHealth	Victorian Health Promotion Foundation
VMIAC	Victorian Mental Illness Awareness Council
WA	Western Australia

Glossary

The way we use language can be powerful. As noted in 'About this report', the Royal Commission aims to use current and respectful terminology, mindful that respectful language can promote awareness, inclusion and empowerment.

People with disability are the experts when it comes to language in this area. We acknowledge that individuals have their own preferences about how they use language. In deciding on the terms the Royal Commission uses, we have been guided by the definitions and principles in the United Nations *Convention on the Rights of Persons with Disabilities* and have consulted with disability experts. We have taken care to recognise diversity in the terms we use. Chapter 16, 'Our theoretical approaches' outlines the theoretical approaches that have guided the way we understand the terms below.

This glossary is included to assist readers in understanding the terms used in this interim report. It does not capture all the terms in the report. The definitions here are not strict legal definitions, but reflect the Royal Commission's evolving understanding of certain key terms. This understanding may change as we continue to listen to what people with disability tell us about language and their experiences. How we define terms may change between this interim report and our final report.

ableism
Ableism refers to a set of beliefs and practices about 'typical' or 'normal' abilities that feed into prejudicial attitudes and the refusal to adapt to the needs of people perceived as inferior or 'abnormal'. See **disablism.**

abuse
For the purposes of this Royal Commission, abuse and violence are best understood together. See **violence and abuse.**

accessible
The term accessible refers to environments, facilities, services, products and information that people are able to use and interact with in a way that suits their needs.

adjustments
Adjustments are necessary and appropriate individualised adaptions or modifications to remove or minimise barriers to a person with disability participating and being included in society. See also **reasonable adjustments.**

advocacy
Advocacy is acting, speaking or writing in support of oneself, someone else or particular issues, including issues affecting people with disability.

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

Australian Disability Enterprises (ADEs)
Australian Disability Enterprises or ADEs are typically not-for-profit organisations providing lower paid employment to some people with disability. Some ADEs were previously known as 'sheltered workshops'.

autonomy
Autonomy refers to a person being able to make their own decisions and exercise choice and control over their own life. Autonomy is sometimes linked to the concept of self-determination, a term which has particular significance for First Nations people. See **self-determination.**

carer
A carer is someone who provides supports to a person with disability on an unpaid basis, often a family member. Some legislation refers to 'carers' and some people with disability prefer the term over 'support person'. See **supports** and **support person**.

closed environments
The term 'closed environments' refers to facilities or places that may deprive people of their liberty by restricting their ability to leave and limiting those who can enter and access the environments. These include prisons and detention centres, forensic disability facilities and secure mental health facilities. See **segregation.**

cognitive disability
Cognitive disability arises from the interaction between a person with cognitive impairment and attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis with others.

'Cognitive impairment' is an umbrella term to encompass actual or perceived differences in cognition, including concentration, processing, remembering, or communicating information, learning, awareness, and/or decision-making.

People with cognitive disability may include, but are not limited to, people with intellectual disability, learning disability, dementia or acquired brain injuries, and some people with autism.

community visitors
Community visitors independently monitor accommodation facilities where people with disability live, such as group homes, boarding houses and Supported Residential Facilities. They report on the adequacy of services provided and whether human rights standards are being met. The role and title may vary between jurisdictions. Community visitors include both paid visitors and volunteers appointed by statute. Some community visitor schemes include visiting people in prisons, forensic disability facilities, mental health units or children in out-of-home care.

cultural respect
Respect for culture, cultural identity and history, cultural needs and cultural concerns are vital for inclusion and respect for the rights of First Nations and culturally and linguistically diverse people with disability in particular.

culturally and linguistically diverse people
Culturally and linguistically diverse people describes and reflects people from a diverse range of cultural and linguistic backgrounds. This may include people born in a non-English speaking country and who have a cultural heritage different from dominant Australian cultures, migrants and refugees (including asylum seekers) who identify as being from culturally and linguistically diverse backgrounds, and people with dual

heritage. Some members of the Deaf community and other Auslan (Australian Sign Language) users also identify as a cultural minority.

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

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

disability
Disability is an evolving concept that results from the interaction between a person with impairment(s) and attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis with others. See **people with disability.**

disablism
Disablism is a term complementary to ableism, which parallels sexism and racism. It focuses on the disablement and disadvantage people with disability experience when society is not structured to include them. See **ableism.**

discrimination
The *Convention on the Rights of Persons with Disabilities* defines discrimination as any distinction, exclusion or restriction on the basis of a personal characteristic such as disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field. See **intersectionality**.

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

exploitation
Exploitation is the improper use of another person or the improper use of or withholding of another person's assets, labour, employment or resources, including taking physical, sexual, financial or economic advantage.

First Nations people/s
The term First Nations people/s refers to Australian Aboriginal and Torres Strait Islander people/s.

group homes
Group homes are houses that accommodate a number of people with disability as their residential home. The term group home may also be used to refer collectively to both the physical accommodation and provision of specialist disability supports to residents in the home.

guardian
A guardian is someone who is appointed by a board or tribunal to make decisions

about another person's health care, finances, accommodation, services, relationships or some other personal matters.

hard of hearing/hearing impaired
The terms 'hard of hearing' and 'hearing impaired' describe those who are unable to hear, have some hearing or become deaf later in life, and whose communication mode is usually by speech. The choice between these two terms usually depends on personal preference. People who are hearing impaired or hard of hearing may rely on hearing assistance devices (such as hearing aids or cochlear implants), lip reading and captions, and some may learn Auslan as a second language later in life. See **deaf/deafness**.

impairment
An impairment is a condition or attribute of a person, for example a condition that means a person cannot see. An impairment, in interaction with attitudinal, environmental and social barriers, may result in a disability. See **disability**.

indefinite detention
Indefinite detention is the detention of an individual without a specific release date.

intersectionality
The term 'intersectionality' refers to a way of understanding a person with disability's unique experience of multi-layered and intersecting discrimination and disadvantage based on their personal characteristics. These characteristics can include age, sex, gender, gender identity, sexual orientation, intersex status, ethnic origin or race, including the particular situation of Aboriginal and Torres Strait Islander people with disability and culturally and linguistically diverse people with disability.

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

letters patent
The letters patent is an official document issued to establish a royal commission. The letters patent contain terms of reference that define the scope of the inquiry.

LGBTIQ+
LGBTIQ+ is an internationally recognised acronym used to describe lesbian, gay, bisexual, trans and gender diverse, intersex, and queer and questioning people and communities collectively.

National Disability Advocacy Program (NDAP)
The National Disability Advocacy Program is a Commonwealth funded program that aims to provide people with disability with access to effective disability advocacy that promotes, protects and ensures their full and equal enjoyment of all human rights, enabling community participation.

National Disability Insurance Agency (NDIA)
The NDIA is a statutory agency responsible for implementing and managing the National Disability Insurance Scheme (NDIS).

National Disability Insurance Scheme (NDIS)
The NDIS was established by the *National Disability Insurance Scheme Act 2013* (Cth) to provide funding directly to eligible people with disability for support and services. See Appendix D for an overview of the NDIS.

NDIS Quality and Safeguards Commission (NDIS Commission)
The NDIS Commission is a statutory agency established to oversee and monitor the quality and safety of NDIS supports and services.

neglect
Neglect includes physical and emotional neglect, passive neglect and wilful deprivation. Neglect can be a single significant incident or a systemic issue that involves depriving a person with disability of the basic necessities of life such as food, drink, shelter, access, mobility, clothing, education, medical care and treatment.

people with disability
Based on the Royal Commission's terms of reference, the term 'people with disability' is defined as people with any kind of impairment, whether existing at birth or acquired through illness, accident or the ageing process, including cognitive impairment and physical, sensory, intellectual and psycho-social disability. See **disability**.

physical disability
Physical disability arises from the interaction between a person with physical impairment and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others.

A physical impairment is an impairment that affects a person's mobility, dexterity and/or speech.

psychosocial disability
Psychosocial disability is a disability that arises from the interaction between a person with a long-term mental health condition (that may be episodic) and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others.

reasonable adjustment
Reasonable adjustment means any adjustment for a person with disability to prevent less favourable treatment and that does not impose an unjustifiable hardship on another person.
See **adjustment**.

restrictive practices
A restrictive practice is any action, approach or intervention that has the effect of limiting the rights or freedom of movement of a person. Restrictive practices include physical restraints, chemical restraints, mechanical restraints, environmental restraints, psychosocial restraints and seclusion.

seclusion
Seclusion is a form of restrictive practice involving the confinement of a person, at any time, by themselves, in a physical space where free exit is prevented.

segregation
Segregation may occur when people with disability are separated from the rest of the community or from settings where people without disability access supports and services.

self-determination
Self-determination has two distinct meanings in the context of this interim report.

First, in a disability context, it refers to the right of a person with disability, with appropriate support, to exercise choice and control over their own life. It is linked to the concept of autonomy. See **autonomy**.

Second, from a First Nations perspective, it refers to the collective right of peoples rather than individuals. It is particularly relevant for First Nations people to have a say over matters that affect them through their own representatives, in a way that existed before colonisation.[1]

sensory disability
Sensory disability arises from the interaction between a person with sensory impairment and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others.

A sensory impairment affects a person's ability to see, hear, touch, smell, have spatial awareness or otherwise be aware of and perceive the world around them.

substitute decision-making
Substitute decision-making refers to a range of processes and regimes that involve a person making decisions on another person's behalf, where (a) the person's legal capacity is removed, (b) the decision-maker can be appointed by someone other than the person concerned,[2] or (c) decisions are made according to the person's 'best interests'. See also supported decision-making.

supports
Supports are any actions, practices, strategies or resources that promote participation and inclusion of a person or people with disability in society.

support person
A support person is someone who provides supports to a person with disability. This may be a family member, friend, or a person contracted for paid or voluntary work. If a person is contracted as a paid or formal voluntary worker, it is appropriate to refer to them as a 'support worker'.

supported decision-making
Supported decision-making refers to a range of processes and approaches that assist people to exercise their legal capacity by supporting them to make decisions about their own lives according to their own will and preferences.

supported independent living (SIL) funding
SIL funding is a category of funding provided by the NDIS to people with high support needs. SIL refers to the approach of funding supports around a weekly roster, developed with a provider, rather than including those supports in an individual's NDIS plan.

terms of reference
The Royal Commission's terms of reference are the nature and scope of our inquiry, as set out in the letters patent. See **letters patent**.

trauma
Trauma refers to the lasting adverse impacts that may arise when a person has lived through an event, series

of events, or set of circumstances that is experienced as physically or psychologically harmful or life threatening.

trauma-informed
Trauma-informed describes frameworks and strategies to ensure that the practices, policies and culture of an organisation and its staff understand, recognise and respond to the effects of trauma and minimise, as far as possible, the risk that people may be re-traumatised.

violence and abuse
Violence and abuse include assault, sexual assault, constraints, restrictive practices (physical, mechanical and chemical), forced treatments, forced interventions, humiliation and harassment, financial and economic abuse and significant violations of privacy and dignity on a systemic or individual basis.

vision impaired/blind
People who are blind or vision impaired have reduced vision or are unable to see. See **sensory disability**.

Endnotes

1 *United Nations Declaration on the Rights of Indigenous People*, GA Res 61/295, UN Doc A/RES/61/295 (2 October 2007, adopted 13 September 2007), art 3.

2 A substitute decision-maker may also be appointed by a person under an enduring power of attorney.

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