



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

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# Overview of responses to the **Health Issues paper**

August 2020

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Please be aware that the content in this Overview may be distressing or raise issues of concern for some readers.

There are a range of services available if you require support after reading this paper. Contact details for these services are located at the end of this paper under the heading 'Counselling and support'.

## Outline

### Health care for people with cognitive disability

The Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability published the *'Health care for people with cognitive disability'* Issues Paper (Health Issues Paper) on 16 December 2019 and invited responses to the paper by 20 March 2020, though responses were accepted after this date.

The Health Issues Paper outlined our preliminary understanding of some of the key issues regarding health care and services for people with cognitive disability that require exploration by the Royal Commission, as well as examples of good practice. Ten questions were asked and responses were invited from the public.

### Purpose of this document

This document provides a brief summary of responses to the Health Issues Paper.

Responses express a range of views and this summary is not an authoritative statement of the contents of the responses nor of the Royal Commission's views of those responses. We will consider all responses received to the Health Issues Paper in the course of our work.

### Scope of this document

This document does **not** summarise what we have heard so far across all other sources of information, including submissions, community forums, private sessions, public hearings or via research projects that relate to health care settings.

However, all information provided to the Royal Commission informs our work. Our Interim Report, due not later than 30 October 2020, will provide more information about what we have heard so far about the health of people with disability and their experiences of violence, abuse, neglect and exploitation.

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The Royal Commission will continue to consider issues related to the health care of people with cognitive disability and seek input in a variety of ways.

## Who responded?

As at 3 June 2020, we received 38 responses to the Health Issues Paper.

Responses were provided by a diverse mix of organisations, advocates and individuals, including five people with disability, five family members of people with disability, and a range of academics and organisations representing people with disability.

We received three responses from organisations who represent First Nations people: the Lowitja Institute, the National Health Leadership Forum (NHLF) Aboriginal and Torres Strait Islander Health and Queensland Aboriginal and Islander Health Council (QAIHC).

We did not receive a response from any organisation which represents culturally or linguistically diverse people with disability.

## What did the responses say?

The responses provide information on the nature and extent of violence, abuse, neglect and exploitation of people with cognitive disability within health care settings.

### Nature and extent of violence, abuse, neglect and exploitation

Many of the responses we received detailed incidences of violence, abuse, neglect and exploitation of people with cognitive disability within health care settings. These included concerns around access to health care (particularly for those in residential services), the use of restrictive practices and involuntary treatment.

### Access to affordable, quality health care

Respondents raised concerns around access to affordable, quality health care particularly for those in residential services.

Communication was consistently identified as a major barrier to accessing health care for some people with cognitive disability. Multiple respondents, including professional bodies, highlighted how health professionals are not always equipped to communicate with people with a cognitive

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disability. Respondents noted that this meant they were not able to conduct a proper health assessment and treatment of conditions.

In addition, respondents told us that a lack of effective communication between people with disability, their carers or support workers and health care professionals can mean health care professionals may not understand certain expressions of pain. For example, this may mean that a person's behaviours may be attributed to the person's disability, rather than reflecting an underlying health issue.

The cost of primary health care was raised as a concern by respondents noting that health issues can become more serious due to lack of timely treatment. The Royal Australian College of General Practitioners (RACGP) observed that 'cost constraints' can delay people with disability seeing a health professional. The Queensland Aboriginal and Islander Health Council (QAIHC) expressed concern that a lack of preventive health care and annual health assessments can lead to chronic health conditions.

Exercise and Sports Science Australia also expressed concern about cost barriers, noting that Medicare only funds five allied health services annually for each person. Clients with cognitive disability and chronic conditions 'often need to see three or more allied health professionals to manage a chronic condition.' This may limit an individual client to 'only one session per practitioner' each year.

Access to mental health services was raised by multiple respondents. RACGP observed that people with cognitive disability have a high prevalence of mental health problems, and that there is a lack of experienced psychiatrists and mental health workers to assess and manage these issues. Autism Aspergers Advocacy Australia also noted a 'scandalous shortage' of psychiatrists equipped to treat people with autism.

The quality of sexual and reproductive health care was also raised as an issue. Family Planning NSW expressed concern about the quality of care for people with intellectual disability, stating 'health services are often inexperienced or avoid providing reproductive and sexual health care and support, particularly where there are sexualised behaviours or a person's capacity to make decisions are of concern'.

Sexual Assault Support Services in Tasmania stated they have been unable to secure funding to train their staff to provide 'tailored supports and interventions' to people with disability. Where they have sought to make referrals to specialist disability services, 'they are not necessarily specialists in sexual assault support and trauma-informed practice.'

## Provision of health care in residential disability services

NSW Ageing and Disability Commission (ADC) provided a response based primarily on reports by Official Community Visitors (OCVs). It highlighted issues regarding the health care of residents in supported accommodation, including a lack of access to health services, including preventive health care.

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ADC said that OCV's have reported:

- residents whose symptoms of recurrent urinary tract infections were overlooked
- residents whose recurrent falls were ascribed to the progression of their disability and ageing, with delays in action to investigate the potential underlying cause
- residents for whom there appeared to be limited and/or delayed action taken in response to signs of weight loss, incontinence, or changes in their health or behaviour.

Oral health was mentioned by multiple respondents, with concerns expressed about support not being provided to residents of group homes to access oral health care or to attend dental appointments. One response wrote of a 'lack of adequate oral hygiene provision or supervision in many group homes'. Another response described a person in residential care who had no visits to the dentist for at least five years.

## Restrictive practices

Several organisations and individuals outlined issues relating to restrictive practices, particularly around the use of physical and chemical restraints.

The Office of the Public Guardian Queensland expressed concern about the 'over-reliance on medications to manage behaviour' and the 'prescribing of anti-libidinal medication' as a chemical restraint. Other responses said it is 'well established' that when people with cognitive disability encounter disruptions to their routines, unfamiliar environments and have limited communication with staff in hospital, these issues can cause what hospital staff perceive as 'behaviours of concern'.

A carer of people with cognitive disability told us that when individuals with an intellectual and/or developmental disability arrive at hospital they are almost always put on antipsychotic medication. This is used as a chemical restraint in an attempt to manage their behaviours because the environmental, communication, and support needs they require are difficult or impossible to provide within the hospital. The response further suggested that these presentations could usually have been prevented through the anticipation and addressing of the issues at an earlier stage.

The Australian College of Emergency Medicine (ACEM) noted that Emergency Departments are 'generally fast paced and busy' and stated that; for some people with autism and other cognitive disorders, this can be perceived as 'neither safe nor secure'. ACEM noted that it is a concern that where people present with or develop an acute behavioural disturbance in the emergency department they are more likely to experience physical and chemical restraint.

The Office of the Public Advocate Victoria (OPA) expressed concern that people with cognitive disability are 'denied safe and comprehensive health care' due to exhibiting 'challenging behaviours'. Their response stated that OPA guardians continue to work with people with cognitive impairment who are subject to restrictive practices in hospitals on an ongoing basis, including where the justification for the practices is the safety of staff.

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## Involuntary treatment

Responses expressed concerns in relation to involuntary treatment. Involuntary treatment refers to medical treatment being provided to a person, without the consent of the person. Several respondents discussed doctors prescribing medicine and contraceptives without consent and parents seeking information about sterilisation without their adult child's consent.

Family Planning NSW expressed concern about the quality of reproductive and sexual health care for people with intellectual disability, highlighting that some doctors provide women with contraception without explaining what it is for, based on the requests of the parent/carers or support person. Women may be told that contraception is only for skincare or other non-contraceptive purposes.

The OPA suggested that some health practitioners are not sufficiently skilled in assessing decision-making capacity and do not understand the various ways in which they are legally obligated to support their patients to exercise their right to make decisions about their health.

## Potential factors that contribute to violence, abuse, neglect and exploitation

Responses raised a range of factors that may contribute to and underpin the experiences of people with disability. These included:

- negative attitudes about disability and the value of people with disability
- a lack of workforce training about the health needs of people with disability in the disability and health sectors
- a lack of coordination and communication between health and disability sectors.

## Negative attitudes about people with disability

Multiple respondents described negative attitudes towards people with cognitive disability, which can impact on the health care they receive. Respondents suggested health professionals may be reluctant or disincentivised to treat patients with disability due to their perception about the quality of life of people with disability, the value of people with disability, or the perceived time required to provide health care.

One respondent wrote that the health care system does not treat people with disability the same as people without disability, 'consistently questioning or denying the value of the lives of people with disabilities. Another response cited research that staff who lacked training in caring for people with intellectual and developmental disability 'tend to stereotype and devalue' the worth of people with disability.

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OPA stated that there are 'deeply rooted discriminatory attitudes that persist within the health sector' and said that 'mainstream health services are often ill-equipped to support clients with cognitive impairment, particularly when patients present with behaviours that seem difficult to manage. Discriminatory attitudes prevail'.

RACGP wrote 'it generally takes much longer than usual to adequately assess and manage patients with cognitive disability as their medical issues are more complex, often associated with communication problems and require extra time to communicate with carers.' RACGP further stated that there 'is a financial disincentive to provide long or prolonged consultations and, as such, GPs may be less inclined to take on large numbers of patients with disability.'

One general practitioner told us that she bulk bills long consultations with patients with disability, and that this causes a 'significant reduction' in her income. She observed that the government relies on doctors to 'partially fund these consultations which is not appropriate and does not guarantee a person with disability having ready access to reliable healthcare'.

Concerns were raised about health staff not consulting or listening to patients with cognitive disability. Speech Pathology Australia outlined 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.

## Lack of workforce training

Communication can be a major barrier for people with cognitive disability, particularly when they are admitted to hospital. Multiple respondents expressed concern that there is a lack of training, expertise and experience across the health care profession including medical, allied health and nursing practitioners on how to overcome these communication barriers.

Multiple respondents noted that health professionals are often not trained in how to listen to people who do not use words to communicate their health issues, including those who use a range of communications methods/devices/tools to communicate.

Concerns were also raised about the need for further training for disability support workers. The Centre for Developmental Disability Health highlighted that disability support workers play a key role in monitoring health status and facilitating peoples' access to health services, and yet most have no or limited training in monitoring the health needs of the people that they support.

The ADC stated that disability support workers tend to act as 'gatekeepers' to health services for people in supported accommodation. Issues can arise where they are not adequately trained to recognise health issues. Lack of health awareness can result in failure to facilitate access to health care, or to otherwise support relevant preventive health care.

Respondents also raised issues around National Disability Insurance Scheme (NDIS) staff having inadequate understanding of health issues. For example, Speech Pathology Australia stated that NDIS planners did not always 'understand their responsibility to fund core supports for people with disability where they face additional barriers or have additional needs in order to participate

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in an episode of care within the health system.’ Speech Pathology Australia suggested that this is ‘separate from the responsibility of the health system to fund health services and supports for people with disability’ and that ‘currently participants face barriers and delays to getting core or capacity building supports included in their plans to help prepare for or manage a planned engagement with the health service.’

## Coordination of care between health and disability services

Many organisations and individuals told us about a gap that can occur between disability and health services that can affect peoples’ access to, and experience of, health care services. They explained to us how both disability and health services can struggle to identify who has responsibility for funded services for people with disability.

OPA stated that instead of being inclusive and making reasonable adjustments, hospitals are ‘overly reliant on NDIS-funded services’. ‘The belief that people with disability should receive specialist care in separate establishments or services continues to permeate hospital staff, management, and the system as a whole’.

Before the NDIS it was common for a support worker to accompany a person to hospital and to stay with the person as their specific needs required. This is no longer possible as a person’s NDIS funding does not provide for this support. This has meant that people with complex needs are entering a health system that knows little about their specific and individual needs.

RACGP stated ‘there has been a tendency for the health and disability sectors to limit and restrict service output to their area of responsibility. This has been further accentuated by the shift from state-based to Commonwealth-based service delivery in the disability sector.’

Respondents told us that there was a lack of holistic planning and responses to support both health and disability needs of people with disability. For example, one NDIS provider noted it can take three months to change an NDIS plan due to a change of circumstances. This can mean that transport is not properly funded in the plan and this can result in people not being able to get to the health services they need.

Respondents particularly favoured viewing health holistically, addressing underlying social determinants of health, poverty, intergenerational trauma and the effects of colonisation. The Lowitja Institute wrote that a health approach focused ‘on health services alone overlooks the importance of social and cultural determinants such as environment and housing, poverty and cultural expression and exchange that are all critical considerations in upholding a human rights-based approach to health.’

Similarly, QAIHC said a ‘whole-life-view is essential in the development of effective health services’.

Responses also discussed a lack of multi-disciplinary health teams to support coordinated care, particularly in adult health services. RACGP suggested that ‘patients with complex conditions such as cerebral palsy see a range of specialists and allied health professionals working in



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multidisciplinary teams within paediatric services’, but ‘this access almost entirely disappears when they become adults’.

Multiple respondents outlined issues that have arisen since implementation of the NDIS. One provider described a range of health care services that were available for people with disability that were no longer available after the introduction of NDIS. These include regular dental check-ups and annual visits to group homes by a psychiatrist. The provider said the visits from the psychiatrist were ‘the only access to mental health services those residents had’.

Once they ended, ‘local public mental health services would not take on the customers with cognitive disability, which left them with no other local community mental health service options’.

Responses also suggested that there are issues around hospitals and health staff not providing discharge information to disability support workers, or planning discharge with disability support workers. In one instance, a person was discharged without allowing a provider sufficient time to make preparations for the person’s new health requirements.

## Responding to violence, abuse, neglect and exploitation in health

Responses described the current mechanisms for reporting violence, abuse, neglect and exploitation as often inadequate, time-consuming, complex and lacking accountability.

Several organisations and individuals expressed concern about what appears to be a lack of a public oversight mechanism to ensure transparency, fairness and equity over health and disability services. One response said ‘the National Disability [Insurance] Agency compliance and risk management focus does not allay this concern, as it appears this compliance framework is about managing the expenditure of funds, rather than protecting the vulnerable.’

RACGP told the Royal Commission that its members have suggested that violence, abuse, neglect or exploitation of people with disability in the health system may not be reported because of:

- 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 healthcare options
- communication barriers
- limited support for people with disability to report.

Recommendations regarding reporting violence, abuse, neglect and exploitation are discussed in the ‘Proposals’ section below.

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## Potential good practices in health care for people with cognitive disability

Respondents provided examples of good or promising practice in health care for people with cognitive disability. We will continue to explore these and other promising and innovative practices through our inquiry.

### Support for decision making

- The *Medical Treatment Planning and Decisions Act 2016 (Vic)* (MTPD Act) legislates supported decision-making as part of medical treatment decisions.

### Coordinated health care

- Aboriginal and Torres Strait Islander Community Controlled Health Care Organisations provide a holistic model of care that is culturally safe for First Nations people with disability.
- Collaborative and multidisciplinary GP-led teams, which have the potential to improve health outcomes for people with cognitive disability, lead to greater financial efficiencies and better use of limited resources.

### Communication and information sharing

Professional bodies and services told us about tools to support communication with people with cognitive disability to meet their health needs. These include:

- The Admission2Discharge (A2D) program which helps hospital staff provide patient-centred care when a person with a cognitive disability is admitted and discharged from hospital.
- My Health Matters Folder produced by the NSW Council for Intellectual Disability. The Folder uses words and pictures to improve communication between people with intellectual disability and their health care providers. Responses recommended the My Health Matters folder be widely implemented across public and private health services. This includes all people in Australia with a disability having an up-to-date A2D folder.
- A one-page profile to be used as a quick reference for health care staff on three important areas concerning an individual: *'What people appreciate about me'*, *'What is important to me'* and *'How to support me'*.
- Hospital passports that provide information about how the person being admitted communicates, how to best support them, and who the patient is as a person.
- The Communication Access Symbol. This symbol is displayed to show consumers that the business or service is communication accessible, where staff are trained around effective communication and tools are available to support communication.

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## Reasonable adjustments

- Reasonable adjustments can include: allowing more time with health professionals for consults and greater flexibility within the Medicare system; providing accessible information about health care; including people with cognitive disability in conversations about their health care; looking for non-verbal cues; respecting caregiver knowledge of the person; familiarising patients to the hospital environment during pre-admission; and, placing them first on the daily list so as to reduce waiting times.
- Hospitals and other physical environments should be designed to be inclusive. The Australasian College of Emergency Medicine suggested the need to design or re-design some settings so that people with cognitive disability felt calm and safe, such as the design and inclusion of quiet spaces in health settings.

## Policy and practice

- The NSW Agency for Clinical Innovation's (2017) framework *Building capability in NSW health services for people with intellectual disability: the Essentials*. This includes resources and self-assessment tools for local health districts and speciality health networks to improve health services to people with an intellectual disability.

# Proposals for change

Numerous proposals for change were made in responses to the issues paper. Proposals can broadly be categorised as follows:

## Funding

- 75% of responses highlighted the need for reform across a number of areas relating to health care funding. These included: more flexible use of NDIS plan funding to allow family and supporters to stay with any client when they are admitted to a general hospital, Medicare rebates for consultations with General Practitioners and specialists should be increased to reflect the real cost of providing ongoing comprehensive, patient-centred care to people with cognitive disability, including home visiting services.
- Extend Medicare to cover dental and oral health care for people with disability not just those within the NDIS system (see below for more discussion of this issue).
- Adequately fund Medicare items that will enable a treating doctor to see a patient with disability for a longer consultation.
- Longer term government funding for Aboriginal Medical Services and other First Nations peoples' specific services to ensure the support needs of Indigenous people with disability are met in a culturally appropriate way, including allowing Indigenous people to stay on country.

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## Education and training

A number of responses suggested a national approach to mandatory education and training in treating patients with disability for all health professionals to build the capability and capacity of the workforce. Education and training was recommended as mandatory in both undergraduate and post-graduate courses for all professions including medical, allied health and nursing, as well as ongoing professional development.

Responses proposed that First Nations people, Culturally and Linguistically Diverse communities, self-advocates, their families, and advocacy organisations should be involved in developing and delivering education and training.

Responses suggested that the education of all medical and allied health professionals and students include training in communication skills when treating people with cognitive disabilities.

Responses also proposed that training should be developed on the principle of valuing people with disability and explaining reasonable adjustments as set out in the *Disability Discrimination Act 1992*.

## Data and research

Responses suggested development of a national data asset on the health of people with intellectual disability. Responses advocated for a national approach to how health outcomes, inequities and disadvantage of people with cognitive disability are reported, recorded, monitored and analysed. Responses suggested a consistent collection of data would better inform policy and service planning. Additionally, responses recommended extending the use of electronic health record data to outline communication, behaviour, meal time and support plan preferences.

## Dental and oral health care

A number of responses proposed reforming the way oral health care is funded and expressed a preference for the Commonwealth to extend the Medicare system to cover dental care and treatment. Responses suggested that reforming the funding model would allow people to obtain basic preventive treatment from local private practitioners. This would relieve the burden on specialist dental units for people with disability. Funding for more specialist dental units for people with disability was also recommended.

## Coordination of care and advance care planning

Responses also suggested a nationwide approach for improved coordinated care between primary care and secondary care services and between the disability and health care sectors. Primary care usually refers to general practice, community-based nursing and allied health professional care. Secondary and tertiary care is usually care provided by medical specialists in the community and through public and private hospitals. This national approach could include dedicated intellectual

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development disability (IDD) teams that coordinate services, adopting a person-centred approach to facilitate health care needs of people with IDD across all contexts and levels of care.

A disability service provider proposed that the National Disability Insurance Agency (NDIA) ‘take an individualised holistic view of a person’, and that NDIS plans should consider ‘the whole of their disability support and health care needs.’ The provider recommended either that a ‘person’s specialist disability support’ be funded by the NDIS when the client is in hospital, or ‘hospitals should be required to provide specialist disability support to people with high intensity disability support needs’.

Responses provided examples of how coordinated care could be used to support people with disability accessing health care, such as by providing information to a medical professional prior to meeting, advising on the person’s communication style, preferred engagement style and issues they’d like to discuss. In addition, responses highlighted the need to develop a comprehensive national process to ensure transition from paediatric to adult care.

## Supported decision-making

Responses recommended the Australian Health Practitioner Regulation Agency (AHPRA), the national organisation responsible for implementing the National Registration and Accreditation Scheme for health practitioners across Australia, require health practitioners to be trained about medical treatment decision-making legislation.

Responses also suggested the NDIA should continue funding volunteer support for decision-making programs and consider the feasibility of rolling out volunteer programs nationally.

## Preventative health care

Two responses support the recommendation from the National Roundtable on the Health of People with Intellectual Disability (2 August 2019; ‘the Roundtable’) that MBS health assessment items for people with intellectual disability be implemented and better promoted to encourage greater uptake.

The MBS item [715, for First Nations people] is used by Aboriginal and Torres Strait Islander Community Controlled Organisations. The use of this item relies on individuals presenting to the clinic for their health assessment. One suggestion to address this is to facilitate outreach-based annual health checks for First Nations people with disability to prevent missed assessments.

Two responses suggested that national annual health checks such as the Comprehensive Health Assessment Program (CHAP) be mandatory for all people with intellectual disability and that the process of engaging with the CHAP program be made more accessible.

One response proposed that governments fund health promotion campaigns to prevent and reduce the risk of chronic health issues in people with disability. For example sexual health and relationships, oral health, healthy lifestyle education programs and cancer screening programs.

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## Specific roles within the health care profession

A number of responses suggested developing specific roles within the health care profession such as:

- more specialist disability and NDIS liaison officers in hospitals and other key health settings to facilitate a more positive and collaborative experience for people with disability, their support staff and families
- increasing the number of specialists in intellectual disability medicine and set targets for the number of medical specialists in intellectual disability
- clinical nurse consultant roles to specialise in dementia-specific palliative care
- there should be an internal capability on call in hospitals at all times who are specifically trained to support people with cognitive disability
- dedicated First Nations disability support and liaison in all hospitals
- access to interpreters in health services and facilities
- national policy on the role of carers in medical settings that identifies both safety requirements and obligations on health practitioners and hospitals.

## Oversight and complaints mechanisms

Responses highlighted the need to make it easier for people with disability to make a complaint about violence, abuse, neglect or exploitation in the health system.

Examples provided included improving reporting pathways. Strategies to do so include:

- engaging with people with cognitive disability to ensure they are aware of and understand the complaints process
- providing training to health care professionals on identifying reports or disclosures from people who may have difficulty with communication
- using accessible communication, information and resources to explain complaints processes such as easy to read documents, screen reader compatible PDFs.
- dedicated disability advocacy teams within health care services
- making the complaints process easy and accessible by providing any reasonable adjustments, offering support so that the person does not feel overwhelmed, uncomfortable or fearful, treating the person with respect, and involving significant others where appropriate.

In addition, responses suggested that there should be legislation that required organisations to follow up on formal and informal complaints and provide feedback to the complainant.

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## How will we use the information we received?

All information provided to us, including all responses to issues papers, is carefully considered by the Royal Commission. It informs our ongoing work, including public hearings, policy processes and our research agenda. It will also inform our Interim and Final Reports and help us to develop our recommendations.

## Counselling and support

Blue Knot Foundation offers specialist counselling support and a referral service for anyone affected by the Disability Royal Commission.

For support please call their national hotline on **1800 421 468** (9am to 6pm AEST Monday to Friday, 9am to 5pm AEST Saturday, Sunday and public holidays).

In addition to the Blue Knot Foundation, the Australian Government provides support to assist people to engage with the Royal Commission. This support includes:

- free legal advisory services provided by National Legal Aid and the National Aboriginal and Torres Strait Islander Legal Services through the Your Story Disability Legal Service
- advocacy support services provided under the National Disability Advocacy Program.

Further information about these supports, including how to access them, is available on the [counselling and support](#) section of our website.



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