



# Health care for people with cognitive disability

## Issues paper

### Introduction

Health is a key area of inquiry for the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (the Royal Commission). People with disability may be subject to violence, abuse, neglect and exploitation in health settings, and the denial of the right to health care may also be a form of neglect.

The Royal Commission wants to understand the experiences of people with cognitive disability in accessing or receiving health care. People with cognitive disability include people with intellectual disability, autism, acquired brain injury or dementia. People with cognitive disability may experience poor health outcomes due to barriers in the health system. Research suggests that people with cognitive disability are more likely to suffer an avoidable death that could have been prevented through appropriate health care.<sup>1</sup>

The purpose of this paper is to invite information and discussion from the public on 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.

We understand that health care of people with cognitive disability is only one issue we need to consider. We invite your ideas on other matters related to health that we should be examining. Based on your feedback and our research, broader experiences of people with disability in the health system will be addressed in issues papers in 2020.

A list of questions is included to assist people and organisations who want to make contributions to the Royal Commission about the provision of health care and services to people with cognitive disability. The questions are a guide. You do not have to answer every question and your response does not have to address any of the questions. Please send in any information that will assist the Royal Commission.

More information about how to respond to this issues paper is at the end of the paper.

## A human rights-based approach

Our terms of reference recognise that Australia has international obligations to take appropriate legislative, administrative and other measures to promote the human rights of people with disability. The right to health is provided for in the *United Nations Convention on the Rights of Persons with Disabilities* (CRPD)<sup>2</sup> and Article 25 recognises the right to the highest attainable standard of health, without discrimination on the basis of disability. The CRPD also provides obligations in respect of habilitation and rehabilitation in Article 26. Australia is also party to four other international human rights instruments which recognise the right to health.<sup>3</sup>

The right to health does not simply mean the right to 'be healthy'.<sup>4</sup> Rather, the right to health contains both entitlements and freedoms.<sup>5</sup> Entitlements include the right to essential primary health care. Freedoms include the right to:

- non-discrimination
- control one's health and body, including sexual and reproductive freedom
- free and informed consent
- be free from non-consensual medical treatment and experimentation
- be free from torture or cruel, inhuman or degrading treatment or punishment.

The particular experience of people with cognitive disability was addressed by the United Nations Committee on the Rights of Persons with Disabilities (the UN Committee) in its recent Concluding Observations on the combined second and third periodic reports of Australia.<sup>6</sup>

The UN Committee recommended that Australia adhere to Article 25 to ensure that

all persons with disabilities and children with disabilities have access to information, on an equal basis with others, and to affordable, accessible, quality and culturally-sensitive health services and equipment ... with particular consideration for ... persons with intellectual or psychosocial disabilities.

## Why is the Royal Commission looking at health care for people with cognitive disability?

Health is critical to support the independence and inclusion of people with disability.<sup>7</sup> It is an enabling right. If a person's health needs are not met, then children and adults with disability may be unable to attend school, access employment opportunities or participate in society. However, research shows that, since the mid-1990s, there has been little progress to address the barriers faced by people with cognitive disability when accessing health care.<sup>8</sup>

Health for First Nations people encompasses spiritual, cultural, emotional and social wellbeing. It recognises that belonging and deep connections to land, culture, spirituality, family, and community are important for wellbeing, and is influenced by past events.<sup>9</sup> There is limited research on the multiple barriers to health care for First Nations people with cognitive

disability,<sup>10</sup> although research suggests that non-Indigenous Australians with disability receive services that First Nations people with disability do not.<sup>11</sup> Culturally and linguistically diverse people with disability may also experience unique barriers in accessing health care. This requires further research and investigation.

## Some issues and barriers

There are a range of issues and barriers that people with cognitive disability may experience with the health system, including mental health and dental and oral health. People with cognitive disability report that medical professionals often don't take the time to explain health issues in accessible ways.<sup>12</sup> This can make it difficult for people with cognitive disability to understand examinations, diagnosis and treatment options and may lead to these not being performed or being performed without informed consent.

Some other examples of barriers and issues are outlined below. These barriers and issues may occur in all health care settings, including hospitals, general practitioner's (GP) clinics, medical centres, community health centres and specialist or consultant offices.

- Barriers to health care for people with cognitive disability can include:
  - communication and physical barriers
  - cost and funding
  - rural and remote access
  - training of health and mental health professionals.
- Attitudes and assumptions, which may influence issues such as:
  - diagnostic overshadowing – where a health professional attributes symptoms to a person's disability rather than to a health issue
  - delayed diagnoses/misdiagnoses
  - prescribing practices, over-prescription, and restrictive practices
  - lack of sexual and reproductive health care.

Since the National Disability Insurance Scheme began, participants, including people with cognitive disability, often report significant issues with the interaction between health systems and the NDIS.<sup>13</sup> Some issues include:

- gaps in funding
- gaps in supports, including support workers and communication supports
- lack of coordination between the health system and the NDIS
- inconsistent information
- delays in hospital discharge planning that mean people are 'stuck' in hospital.<sup>14</sup>

The Royal Commission is also interested in hearing about other issues and barriers that people with cognitive disability experience in accessing or receiving health care.

## Questions

Please answer as many of these questions as you wish. You do not need to answer them all and your response does not have to address any of the questions. If you want to tell us about violence, abuse, neglect or exploitation that was experienced by you or another person with cognitive disability when accessing or receiving health care we encourage you to make a submission via the Royal Commission's website. Our website is [disability.royalcommission.gov.au/support](https://disability.royalcommission.gov.au/support).

### Question 1:

What do you think about the quality of health care for people with cognitive disability?

### Question 2:

A. If you are a person with cognitive disability, can you tell us about any problems you have had in getting health care?

B. Can you tell us about any barriers that people with cognitive disability have experienced in accessing health care?

### Question 3:

A. If you are a person with cognitive disability, can you tell us about any problems you have had with the NDIS and getting health care?

B. Can you tell us about any problems that people with cognitive disability have had with the NDIS and accessing health care?

### Question 4:

A. What do you think should be done to fix the problems people with cognitive disability have in getting health care?

B. How could the NDIS and health systems work better for people with cognitive disability?

### Question 5:

Why do people with cognitive disability experience violence, abuse, neglect or exploitation in health care? What are the causes?

### Question 6:

A. Is the violence, abuse, neglect or exploitation that people with cognitive disability experience, different in doctor's or GP's surgeries, medical centres, hospitals, specialists or consultants?

B. Is the violence, abuse, neglect or exploitation that people with cognitive disability experience, different in public, private or not-for-profit health care?

Question 7:

A. Are experiences of violence, abuse, neglect or exploitation in health care different for particular groups of people with cognitive disability?

B. Are experiences of violence, abuse, neglect or exploitation in health care different for First Nations and culturally and linguistically diverse people with cognitive disability?

C. How does a person's gender, age, or cultural or sexual identity impact on people with cognitive disability getting health care?

Question 8:

A. What could prevent people with disability experiencing violence, abuse, neglect or exploitation in health care?

B. What would make a person with cognitive disability feel safe when getting health care?

C. Can you give us any examples?

Question 9:

A. What would stop a person with cognitive disability reporting violence, abuse, neglect or exploitation in health care?

B. What would make it easier for a person with cognitive disability to complain about violence, abuse, neglect or exploitation in health care?

Question 10:

Have we missed anything? What else should we know?

## Responses to this issues paper

Responses to this issues paper can be provided:

- by email to [DRCEnquiries@royalcommission.gov.au](mailto:DRCEnquiries@royalcommission.gov.au)
- by letter to GPO Box 1422, BRISBANE QLD 4001
- by phone on 1800 517 199 or +61 7 3734 1900 (between 9:00am to 6:00pm AEDT Monday to Friday). We can make a time with you to take your response over the phone.
- by audio recording

- by video recording.

Responses can be in any language. The Royal Commission will translate the response to English.

If possible, please provide your responses by **20 March 2020**. Responses will also be accepted after this date.

## Support to respond to our questions

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
- emotional support services provided by the Blue Knot Foundation
- advocacy support services provided under the National Disability Advocacy Program.

Further information about these supports, including how to access them, is available on our website. Our website is [disability.royalcommission.gov.au/support](https://disability.royalcommission.gov.au/support).

## Consenting to the publication of your responses

All responses will inform the work of the Royal Commission. We will not publish your response if you don't want us to. Please indicate if you consent to your response being made public on the Royal Commission website and, if so, whether you would like it to be published in a de-identified form.

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<sup>1</sup> Julian Trollor et al, 'Cause of death and potentially avoidable deaths in Australian adults with intellectual disability using retrospective linked data' [2017] (2017) *BMJ Open* 7.

<sup>2</sup> United Nation Convention on the Rights of Persons with Disabilities, opened for signature 30 March 2007, 2515 UNTS 3 (entered into force 3 May 2008) arts 23(1)(c), 25) [www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html](http://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html)

<sup>3</sup> United Nations International Covenant on Economic, Social and Cultural Rights, opened for signature 16 December 1966, 993 UNTS 3 (entered into force 3 January 1976) art 12; United Nations International Convention on the Elimination of All Forms of Racial Discrimination, opened for signature 21 December 1965, 660 UNTS 195 (entered into force 4 January 1969) art 5(iv); United Nations Convention on the Elimination of All Forms of Discrimination against Women, opened for signature 1 March 1980, 1249 UNTS 13 (entered into force 3 September 1981) arts 10(h), 11(1),(f), 12, 14(2)(b), 16(1)(e); United Nations Convention on the Rights of the Child, opened for signature 20 November 1989, 1577 UNTS 3 (entered into force 2 September 1990) arts 24, 25.

<sup>4</sup> UN Committee on Economic, Social and Cultural Rights (CESCR), *General Comment No. 14: The Right to the Highest Attainable Standard of Health (Art. 12 of the Covenant)*, 11 August 2000, E/C.12/2000/4

<sup>5</sup> UN Committee on Economic, Social and Cultural Rights (CESCR), *General Comment No. 14: The Right to the Highest Attainable Standard of Health (Art. 12 of the Covenant)*, 11 August 2000, E/C.12/2000/4

<sup>6</sup> CRPD/C/AUS/CO/2-3, Adopted by the UN Committee at its twenty-second session (26 August – 20 September 2019), Advanced Unedited Version, 23 September 2019

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<sup>7</sup> Social Inclusion Board, Government of South Australia, 'Strong Voices: A Blueprint to Enhance Life and Claim the Rights of People with Disability in South Australia (2012-2020)' (October 2011).

<sup>8</sup> Eric Emerson et al., 'A Fair Go?: Measuring Australia's Progress in Reducing Disadvantage for Adults with Disabilities (2001-2016)', (Melbourne: The Centre of Research Excellence in Disability and Health, 2018).

<sup>9</sup> National Aboriginal Community Controlled Health Organisation. *Aboriginal Health*. 2019. Available at [Naccho Aboriginal Health](#).

<sup>10</sup> Meera Roy and Sivasankaran Balaratnasingam, 'Intellectual Disability and Indigenous Australians: An Overview', (6, 2014), 363-72, 367.

<sup>11</sup> Minerva Concepcion Rivas Velarde, 'Addressing Double Layers of Discrimination as Barriers to Health Care: Indigenous Peoples with Disabilities', *Ab-Original: Journal of Indigenous Studies and First Nations and First Peoples' Cultures*, 1/2 (2018), 269-78, 272.

<sup>12</sup> Jenny Ziviani et al, 'Meeting in the middle: improving communication in primary health care consultations with people with an intellectual disability' (2004) 29(3) *Journal of Intellectual and Developmental Disability* 211, 219; Magda Wullink et al, 'Doctor-patient communication with people with intellectual disability - a qualitative study' (2009) 82 *BMC Family Practice*.

<sup>13</sup> Centre for Applied Disability Research, Research to Action Guide, *Working collaboratively at the interface of disability and health services*, 2016, available at [www.cadr.org.au](http://www.cadr.org.au).

<sup>14</sup> Joint Standing Committee on the National Disability Insurance Scheme. *Report on the transitional arrangements for the NDIS*. February 2018.