National Centre of Excellence in Intellectual Disability Health

Committee Secretary
Senate Standing Committees on Community Affairs
PO Box 6100
Parliament House
Canberra ACT 2600
Sent via email: community.affairs.sen@aph.gov.au

29 September 2025

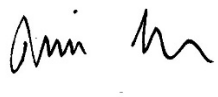
Dear Secretary,

Inquiry on Australian Centre for Disease Control Bill 2025 and Australian Centre for Disease Control (Consequential Amendments and Transitional Provisions) Bill 2025 (ACDC Bill)

We write on behalf of the National Centre of Excellence in Intellectual Disability Health. We trust the Committee will find this information useful in the development of its report. We would welcome the opportunity to appear at a Committee hearing.

Should you require further information about this submission, please do not hesitate to contact me at 0418 635 630 jim@cid.org.au

Sincerely;



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In conjunction with:

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About us

The National Centre of Excellence in Intellectual Disability Health ('the Centre') is an important initiative supported by the Australian Government Department of Health and Aged Care. The Centre is a consortium of nine organisations including:

1. UNSW Sydney,
2. Centre for Disability Studies (University of Sydney),
3. Council for Intellectual Disability,
4. Down Syndrome Australia,
5. First Peoples Disability Network,
6. Queensland Centre of Excellence in Autism and Intellectual Disability Health
7. Queenslanders with Disability Network,
8. The Kids Institute and,
9. University of Melbourne.

It also includes another 56 health and disability organisations as partners and collaborators. The vision of the Centre is to ensure that the 500,000 people with intellectual disability in Australia receive the highest attainable level of healthcare.

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EXECUTIVE SUMMARY

People with intellectual and other disabilities must be a priority focus of the ACDC Bill

This is needed in view of the following factors:

1. People with disability in Australia suffer marked health inequalities. For the 550,000 people with intellectual disability, the established inequalities are particularly stark including reduced rates of preventative health care and highly elevated rates of avoidable hospitalisation and death
2. The Disability Royal Commission found people with intellectual and other cognitive disabilities to experience ongoing "systemic neglect" in the Australian health care system.
3. The COVID-19 Response Inquiry Report of the Commonwealth Government highlighted inadequacies in government action for people with disability during the pandemic and emphasised the need for ongoing input to health protection mechanisms by people with disability lived experience and expertise including through an advisory mechanism like the COVID-19 Disability Advisory Committee.
4. As the Australian Commission on Safety and Quality in Health Care has highlighted:
    a. Barriers to appropriate healthcare for people with intellectual disability include direct and indirect discrimination and negative attitudes leading to misdiagnosis or delayed diagnosis with the person's symptoms being attributed to their intellectual disability, and in turn leading to preventable hospitalizations, chronic disease and early mortality.
    b. Cognitive biases towards people with intellectual disability include assumptions about a person's quality of life, their ability to gain new skills and their capacity to participate in health care planning. Cognitive bias may influence decisions about providing proactive treatment, rehabilitation, preventative health care and end of life care.

There is a clear danger that, if people with intellectual disability are not an explicit focus of the ACDC, their issues will not be understood, considered and addressed.

Senators will note that we repeatedly say "intellectual and other disabilities" in this submission. It is vital that people with disabilities not be seen as one homogeneous group and that the particular stark health inequalities faced by people with intellectual disability are given specific attention based on the expertise in their lived experience and their sector.

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Some things people with intellectual disability said during the COVID-19 pandemic

"If I got sick I would want to know how food would get to my house and if my support worker could come to my house."

"The restrictions over the Easter long weekend really affected me. My mental health was bad. I had a nervous breakdown. I couldn't see my parents over Easter. It upset me so much. I was alone… I have a phone but technology is not easy – it's not easy for me to do video calls and I don't have everything set up."

"I just want all information in Easy Read."

Steps to make people with intellectual disability a priority for the ACDC Bill

A priority focus on people with intellectual disability should be ensured by:

1. Inclusion of equity for people with intellectual and other disabilities in the factors that the Director-General of the ACDC must have regard to in exercising their functions.
2. Ensuring that expertise in intellectual and other disability is present on the ACDC Advisory Council.
3. The ACDC having a disability reference group with community representation similar to the Covid Disability Advisory Committee.
4. Re-establishing or maintaining a disability advisory group to provide advice to the Australian Health Protection Committee. This group's position should be equal to that of consultative bodies for other priority populations (This could be the same group as our proposed ACDC disability advisory group.)
5. The ACDC have a senior staff member with specific expertise in the health of people with intellectual and other disability.

Recommendations for amendments to the Bill

We ask the Parliamentary Committee to recommend the following amendments to the Bill:

1. Add an additional objective in Section 2 in relation to the list of things that the Director-General must have regard to in exercising their functions:

   "the need to ensure equity in disease control for disadvantaged populations including First Nations people, people with intellectual and other disabilities, people with mental illnesses, people from culturally and linguistically diverse backgrounds and LGBTIQ+ people, and taking account of intersectional disadvantage."

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2. In section 30, Appointment of Advisory Council members, enhance the focus on disadvantaged populations including by
    a. Adding “the health of people with intellectual and other disabilities” to the eligibility factors in subsection (4)
    b. Requiring that at least one appointed member to the Advisory Council has expertise in the health of people with intellectual and other disability.

3. Add a provision to the Bill requiring that the Centre have reference groups focused on the needs of disadvantage populations including people with disability.

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SUBMISSION

FOCUS

In this submission we argue that the Australian Centre for Disease Control Bill be amended to ensure that Australia's Centre for Disease Control (ACDC) meets the stark health inequalities facing people with intellectual disabilities.

Amendment to the Bill should ensure:

1. Inclusion of equity for people with intellectual and other disabilities in the factors that the Director-General of the ACDC must have regard to in exercising their functions.
2. That expertise in intellectual and other disability is present on the ACDC Advisory Council.
3. That the ACDC has a disability reference group with community representation similar to the former Covid Disability Advisory Committee.

HEALTH INEQUALITIES FACING PEOPLE WITH INTELLECTUAL DISABILITY

In Australia, approximately 550,000 people with intellectual disability face stark health inequalities and multiple barriers to accessing health care that meets their needs. With their close families, over two million people are affected.

The experience of this group was pivotal to the finding by the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (DRC) of systemic neglect in health care for people with cognitive disability.

In comparison to the general population, health outcomes for people with intellectual disability are characterised by:

- Premature mortality occurring 27 years earlier[2].
- More than double the proportion of potentially avoidable deaths[2].
- Four times the rate of potentially preventable hospitalisations[3].

Compared to people in the general population, health service interactions for people with intellectual disability are:

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- Over-represented, with hospitalisations and emergency presentation rates being twice as high.[4]
- Costly, with:
  - Admissions being on average twice as long and twice as expensive.[4]
- Inefficient:
  - With higher rates of representation to emergency departments and inpatient units following discharge from mental health facilities, even for first-ever admission.[5]
  - Even with a clear clinical pathway for epilepsy and seizure admissions, there are significant disparities. Age-standardised admission rates per 100,000 people are 21 times higher, with longer admissions and higher readmission rates within 30 days.[6]

Australians with intellectual disability also are less likely to have their preventative health care needs met through primary care compared to the general population.[8,9] This contributes to high acute care service use.[10]

PEOPLE WITH DISABILITY IN THE COVID-19 PANDEMIC

Report of the Commonwealth COVID-19 Response Inquiry

The Report of the Commonwealth Government COVID-19 Response Inquiry | PM&C includes a detailed chapter focused on people with disability. The Inquiry Report was critical of various aspects of government response to the needs of people with disability during the pandemic. It also stressed the importance of mechanisms to ensure government health responses are informed by people with lived experience and expertise in disability.

Key findings of the Response Inquiry include:

- **People with disability were at increased risk**

In any public health emergency, some people with disability are likely to be at greater risk than the general population. This stems from combination of clinical factors contributing to a greater risk of severe disease or death from communicable diseases, and barriers to accessing and using health services.
The COVID-19 pandemic revealed poor coordination of responses for people with disability across government.

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The Inquiry recommended that pandemic plans should take into account potential risks to people with disability due to the disproportionate health, social and economic impacts they are likely to face.

- **The vaccine and testing rollout for people with disability was deficient**

The Disability Royal Commission described the vaccine rollout for people with disability as 'seriously deficient'.[11]

The Australian National Audit Office (ANAO) also noted the slow rollout, particularly for people in residential disability settings. The found the vaccination rate of NDIS residential disability residents did not reach 80 per cent double vaccinated until November 2021. This was approximately the same time as the Australian population aged 16 years and over, even though residential disability workers and residents were eligible to get vaccinated six months earlier than the majority of Australians aged 16 years and over. [12]

People with disability also had difficulty accessing testing. Item limits on rapid antigen tests ignored the requirement for people with disability to test every time a new support worker came into their home. Many PCR testing sites were inaccessible for people who could not drive or were unable to queue for a long time.

- **Mental health impact**

Many people with disability experienced significant mental health challenges during the pandemic. The Australian Institute of Health and Welfare found that 29 per cent of adults with disability had high or very high levels of psychological distress in 2021, compared with 17 per cent of adults without disability.[13]

- **Data systems were revealed as inadequate**

Robust epidemiological data on people with disability and sharing of evidence on best practice are critical elements of an effective pandemic response. The Australian Government's data systems, analytic capability, linkages and data transparency did not adequately support informed evidence-based decision-making, planning and communication during the crisis.

[We at the National Centre of Excellence in Intellectual Disability Health note - Critically, it was revealed that there was no effective mechanism for accurately identifying people with disability, by disability type. Specific visibility of infections, outcomes and vaccination rates for people with disability required bespoke linkages with inherent delays. Further, the relative lack of analytic capacity and expertise in data analysis at the disability/health interface magnified these delays.]

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The Inquiry emphasised that robust data on people with disability is critical to an effective pandemic response. Interconnected health and human services data systems that identify people with disability by nature of disability and by their level of supports, would enable population health insights and tailored public health responses for people with disability.

- **Governments must learn from the COVID-19 experiences of people with disability**

It is essential that governments learn from the experience of the COVID-19 pandemic to ensure people with disability have full and equal access to health care, information and essential services in future public health emergencies.

- **The Government's pandemic Disability Advisory Committee played a key role**

The Advisory Committee on the Health Emergency Response to COVID-19 for People with Disability (the Disability Advisory Committee) included representatives of people with lived experience of disability, disability organisations and government officials.

The Disability Advisory Committee played a significant role in improving engagement with the disability sector and had a genuine and positive impact on policy developments.

[We at the Centre note that the Committee worked effectively to provide advice and practical steps which substantially accelerated vaccine and treatment availability, access, and prioritisation.]

The presence of people with lived experience and expertise on the Disability Advisory Committee was critical, given the lack of specialised knowledge and experience of disability in government.

There was widespread consensus among stakeholders that the Disability Advisory Committee or a similar body should be maintained to ensure the voices of people with disability are heard in a future crisis. The Disability Royal Commission recommended the Disability Advisory Committee or a similar body be maintained after the pandemic came to an end.

The Inquiry recommended that Government should make the Advisory Committee for the COVID 19 Response for People with Disability, or a similar advisory body, a permanent subcommittee of the Australian Health Protection Committee. The advisory body should also have clear mechanisms to feed into the Disability and Health Sector Consultation Committee

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The permanent advisory structure for people with disability should have a role consistent with the National Aboriginal and Torres Strait Islander Health Protection subcommittee and the Aged Care Advisory Group, including reporting to the Australian Health Protection Committee.

Clarity in responsibilities needs to be backed up by capability and knowledge about disability across all relevant departments and agencies.

[We note that the Department of Health, Disability and Aged Care has made the previous Advisory Committee for the COVID 19 Response for People with Disability a working group under the Disability and Health Sector Consultation Committee (DHSCC), but a meeting of the group has not been called since 2023.]

- **Access to tailored and disability-specific health information is vital**

Communications for people with disability must be easily accessed, understood and tailored to the diverse experiences and needs of people with disability.

[We at the Centre note that in the very early stages of the pandemic, there was no accessible information for people with intellectual disability.]

The Inquiry recommended that communications for people with disability must be easily accessed, understood and tailored to the diverse experiences and needs of people with disability.

Government should develop a communication strategy for use in national health emergencies that ensures Australians, including those in priority populations, families and industries, have the information they need to manage their social, work and family lives. The strategy should account for the distinct communications preferences and requirements of priority populations

- **Disability support workers and carers need assistance to continue providing essential services in a pandemic.**

The Inquiry recommended that support workers and carers need to be recognised as essential, given tailored infection prevention and control training and provided with priority access to PPE and vaccination.

- **Plan ahead to be ready for another pandemic**

The Inquiry recommended that governments develop updated health emergency planning and response arrangements including management plans for priority populations under the National Communicable Disease Plan, including for people with disability.

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- **Progress development of the Australian Centre for Disease Control**

The Inquiry recommended that, as well as then proposed functions, the Centre should have additional functions to map and enhance national pandemic detection and response capability.

What people with intellectual disability said in the pandemic

Early in the pandemic, the Council for Intellectual Disability undertook consultations with people with intellectual disability. The report from that consultation is at *COVID-19 leave no one behind - Council for Intellectual Disability*

Here are examples of key insights from participants in the consultation:

> *"I think the Prime Minister makes things very confusing, mumbo jumbo. It is easier to understand what the Premier [in Tasmania] says. The Premier is on TV once a day to explain what is happening and he does it quite well. He speaks slowly and explains things well."*
>
> *"My big concern is about getting the virus…I already have health issues and get really bad asthma, it would be really bad for me…I don't have heaps of people that can help me if I got sick. My parents are both dead…Maybe my support coordinator or someone from the NDIS could help me if I needed to. "*
>
> *"I'm scared about getting tested if I have to – does it hurt to get tested? I have seen pictures that they put something up your nose, does this happen?"*
>
> *"If I got sick I would want to know how food would get to my house and if my support worker could come to my house."*
>
> *"…I was in seclusion for 4-5 days in my room at the group room at [service provider] and I was given meals very kindly by the carers and showers, drinks, food, medication and some sweets and essential items – I was also asked to wear masks, plastic gloves, hand washing and some hand sanitizer with social distancing rules. I felt suicidal ideas and feelings… I wanted to come out of my room and call Lifeline."*
>
> *"The restrictions over the Easter long weekend really affected me. My mental health was bad. I had a nervous breakdown. I couldn't see my parents over Easter. It upset me so much. I was alone… I have a phone but technology is not easy – it's not easy for me to do video calls and I don't have everything set up."*
>
> *"I just want all information in Easy Read."*

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PEOPLE WITH INTELLECTUAL AND OTHER DISABILITIES MUST BE A PRIORITY FOCUS OF THE ACDC BILL

This is needed in view of the following factors:

1. People with disability suffer marked health inequalities. For people with intellectual disability, the established inequalities are particularly stark including reduced rates of preventative health care and highly elevated rates of avoidable hospitalisation and death
2. The Disability Royal Commission found people with intellectual and other cognitive disabilities to experience ongoing "systemic neglect" in the Australian health care system.
3. The COVID-19 Response Inquiry Report of the Commonwealth Government highlighted inadequacies in government action for people with disability during the pandemic and emphasised the need for ongoing input to health protection mechanisms by people with disability lived experience and expertise including through an advisory mechanism like the COVID-19 Disability Advisory Committee.
4. As the Australian Commission on Safety and Quality in Health Care has highlighted:
    a. Barriers to appropriate healthcare for people with intellectual disability include direct and indirect discrimination and negative attitudes leading to misdiagnosis or delayed diagnosis with the person's symptoms being attributed to their intellectual disability, and in turn leading to preventable hospitalizations, chronic disease and early mortality.

    b. Cognitive biases towards people with intellectual disability include assumptions about a person's quality of life, their ability to gain new skills and their capacity to participate in health care planning. Cognitive bias may influence decisions about providing proactive treatment, rehabilitation, preventative health care and end of life care. https://www.safetyandquality.gov.au/publications-and-resources/resource-library/nsqhs-standards-user-guide-health-care-people-intellectual-disability

There is a clear danger that, if people with intellectual disability are not an explicit focus of the ACDC, their issues will not be understood, considered and addressed.

Senators will note that we repeatedly say "intellectual and other disabilities" in this submission. It is vital that people with disabilities not be seen as one homogeneous

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group and that the particular stark health inequalities faced by people with intellectual disability are given specific attention based on the expertise in their lived experience and their sector.

A priority focus on people with intellectual disability should be ensured by:

1. Inclusion of equity for people with intellectual and other disabilities in the factors that the Director-General of the ACDC must have regard to in exercising their functions.
2. Ensuring that expertise in intellectual and other disability is present on the ACDC Advisory Council.
3. The ACDC having a disability reference group with community representation similar to the Covid Disability Advisory Committee.
4. Re-establishing or maintaining a disability advisory group to provide advice to the Australian Health Protection Committee. This group's position should be equal to that of consultative bodies for other priority populations (This could be the same group as our proposed ACDC disability advisory group.)
5. The ACDC have a senior staff member with specific expertise in the health of people with intellectual and other disability.

RECOMMENDATIONS FOR AMENDMENTS TO THE BILL

We ask the Parliamentary Committee to recommend the following amendments to the Bill:

1. Add an additional objective in Section 2 in relation to the list of things that the Director-General must have regard to in exercising their functions:

   "the need to ensure equity in disease control for disadvantaged populations including First Nations people, people with intellectual and other disabilities, people with mental illnesses, people from culturally and linguistically diverse backgrounds and LGBTIQ+ people, and taking account of intersectional disadvantage."

2. In section 30, Appointment of Advisory Council members, enhance the focus on disadvantaged populations including by
   a. Adding "the health of people with intellectual and other disabilities" to the eligibility factors in subsection (4)

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b. Requiring that at least one appointed member to the Advisory Council has expertise in the health of people with intellectual and other disability.

3. Add a provision to the Bill requiring that the Centre have reference groups focused on the needs of disadvantage populations including people with disability.

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