



19 December 2023

Dear Robyn Kruk AO, Professor Catherine Bennett, and Dr Angela Jackson,

## **Re: Commonwealth Government COVID-19 Response Inquiry**

Inclusion Australia is the national Disability Representative Organisation representing the rights and interests of Australians with an intellectual disability and their families. Founded in 1954, our mission is to work to make sure people with an intellectual disability have the same opportunities as people without disability. Our policy team includes several policy officers with an intellectual disability and our policy and advocacy work is directly shaped by people with an intellectual disability and their families.

Inclusion Australia's strength comes from our state members who use their combined experience and expertise to promote the inclusion of people with an intellectual disability. Our state members are:

- Developmental Disability Western Australia (DDWA) – Western Australia
- NSW Council for Intellectual Disability (CID) – New South Wales
- Parent to Parent (P2P) – Queensland
- South Australian Council on Intellectual Disability (SACID) – South Australia
- Speak Out Advocacy – Tasmania
- Victorian Advocacy League for Individuals with Disability (VALID) – Victoria

For more than two years we have had a Northern Territory branch of Inclusion Australia based in Darwin. Our work in the Northern Territory is informed by a Local Steering Group that includes representatives from advocacy and other territory-based organisations.

Thank you for the opportunity to provide a submission to the Commonwealth Government's COVID-19 Response Inquiry.

We do not have capacity to undertake extensive consultation with our community to shape our response and provide detailed recommendations, but the COVID-19 pandemic and governments' responses have had a considerable impact on the lives of people with an intellectual disability and their families. We would like to share previous work we have done on this important topic, and outline a range of evidence to the Independent Panel highlighting that:

- People with an intellectual disability were—and continue to be—disproportionately impacted by the COVID-19 pandemic
- The vulnerabilities of the healthcare and income support systems in Australia revealed and exacerbated by the pandemic (though many of those vulnerabilities far

pre-dated the pandemic itself) put the lives and livelihoods of people with an intellectual disability at tremendous and disproportionate risk.

Based on this, we wish to strongly recommend to the Independent Panel that the Inquiry **consider the distinct ways the COVID-19 pandemic impacted people with an intellectual disability and their families, and include specific measures aimed to address these issues in your recommendations** to the Department of Prime Minister and Cabinet in relation to response measures in the event of future pandemics.

Our previous advocacy in relation to the Australian Government's COVID-19 vaccine national rollout strategy comprises the following, including a range of decision-making resources for people with an intellectual disability:

- [Barriers to COVID-19 vaccination for people with an intellectual disability](#)
- [Disability Royal Commission—written statement of Catherine McAlpine, CEO of Inclusion Australia](#)
- [Disability Royal Commission—written statement of Kevin Stone, CEO of the Victorian Advocacy League for Intellectual Disability \(VALID\)](#)
- [Media release—People with disability need urgent action on vaccines to stay safe from COVID](#)
- [COVID Vaccine – Yes or No – How to Decide: a decision-making resource for people with an intellectual disability](#)
- [Living with COVID—an animation by Inclusion Australia and Speak Out](#)
- [Free COVID-19 vaccine rollout webinars](#)
- [Disability advocate shares her COVID vaccine experience](#)
- [‘Left in lockdown’—People with disability call for a COVID Recovery Plan.](#)

We believe the evidence provided in our submission, and in the resources listed above, will help the Panel to consider the unique ways the COVID-19 pandemic, and the Commonwealth Government's response to it, impacted people with an intellectual disability and their families. As the World Health Organisation noted in 2020:

*“Addressing the current challenges and barriers faced by persons with disabilities requires commitment and creativity but it also presents a unique opportunity to design and implement disability-inclusive COVID-19 response and recovery, and build more inclusive and accessible societies, in consultation with persons with disabilities”.*

We strongly agree with this statement, especially its aspiration that the COVID-19 pandemic should be used as an **opportunity to address the inequities faced by people with an intellectual disability in any future pandemic response and recovery plans and build a more inclusive society as a whole.**

We also note that the findings of the COVID-19 Response Inquiry will be relevant to the development of the new Australian Centre for Disease Control (CDC). We believe the evidence contained in this submission will be essential to the development of the CDC in ensuring it is fit for purpose and appropriately targeted in its scope and activities.

Thank you again for considering our submission. We warmly invite any further opportunities to consult on any of the issues raised in this letter.

Kind regards,

A handwritten signature in purple ink, appearing to read 'Catherine McAlpine', with a stylized flourish at the end.

**Catherine McAlpine**  
**Chief Executive Officer**



# Submission to the Commonwealth Government's COVID-19 Response Inquiry

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### **A note on accessibility**

Given the impact of the COVID-19 pandemic on people with an intellectual disability and their families, this inquiry is very important to our community. We wish to note that it would be very valuable that, when public, the report to the Department of Prime Minister and Cabinet be translated into an accessible format, ideally Easy Read.

This will ensure our community can engage with your findings and understand how any response measures in the event of future pandemics may impact their experiences. We sincerely thank the Independent Panel members in advance for this, and warmly invite any further conversations on how to implement these inclusive practices if that would be useful.

## Background

During and since the COVID-19 pandemic, people with an intellectual disability—having already been much less likely to access healthcare or to participate and be included in the community, as we discuss below—were disproportionately affected by its health, social and economic impacts. This highlighted key vulnerabilities in the systems designed to care for them.

We understand the current inquiry is focussed on the Commonwealth Government’s response to the COVID-19 pandemic, and not the operations of the health or social security system in their entirety.

However, we believe it is crucial to highlight the ways the inequities perpetuated by these systems, many of which predated the pandemic itself, impacted people with an intellectual disability during the pandemic, especially in relation to Australia’s healthcare and income support systems—two important aspects of the Inquiry’s Terms of Reference.

As the national voice for people with an intellectual disability, we continue to call on all Australian governments—as we did throughout the pandemic—to acknowledge that people with an intellectual disability must be recognised and supported as ‘vulnerable persons’ for the purposes of COVID-19 planning. This requires all government agencies and government funded service providers to recognise and act on the fact that, as people made significantly more vulnerable by a range of systemic failures, people with an intellectual disability have distinct needs that require additional support. This must be considered and appropriately planned for in any future pandemic plans and responses made by the Commonwealth Government, including through targeted, sustainable funding.

## Health and economic inequities

About 1.8% of the Australian population have an intellectual disability, or around 450,000 people.<sup>1</sup> There is a growing body of evidence that shows that people with an intellectual disability experience many barriers to accessing healthcare services—including oral healthcare and mental health services—and that these services are generally not inclusive. These barriers include:

- Health professionals’ lack of understanding of intellectual disability, and lack of implementation of human-rights, inclusive and evidence-based approaches within healthcare settings
- Negative attitudes or assumptions about people with an intellectual disability, including a false assumption that some people with an intellectual disability cannot make decisions or give informed consent

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<sup>1</sup> UNSW Department of Developmental Disability Neuropsychiatry. (2023). ID Health Data Portal. Retrieved from: <https://idhealthdataportal.unsw.edu.au/about>

- Lack of flexibility and reasonable adjustments to meet a person’s needs
- A siloed approach to healthcare management that does not recognise the complexity of health-related issues that people with an intellectual disability may experience, which may involve accessing care from several departments that do not interface well.<sup>2</sup>

### **Poorer access to primary health and mental health care**

As a result of the lack of inclusivity within healthcare services generally, research shows that people with an intellectual disability experience significantly poorer health outcomes compared to other people with disability and people without disability, including:

- More than twice the rate of avoidable deaths
- Twice the rate of emergency department and hospital admissions
- Substantially higher rates of physical and mental health conditions—while simultaneously lower rates of detection of illness, particularly of mental illness
- Significantly lower rates of preventative healthcare and underdiagnosis of chronic and acute health conditions.<sup>3</sup>

In terms of mental health—which is an important aspect of the COVID-19 Response Inquiry’s terms of reference—it is estimated that more than half (57%) of people with an intellectual disability also have a mental health condition.<sup>4</sup> However, across Australian states and territories, people with an intellectual disability are largely excluded from mental health policy and not recognised in healthcare settings as having an increased risk of experiencing mental ill-health.<sup>5</sup>

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<sup>2</sup> Troller, J., and Small, J. (2019). Health Inequality and People with Intellectual Disability—Research Summary. Retrieved from: <https://cid.org.au/wp-content/uploads/2019/07/Research-Analysis-Health-Status-of-People-With-Intellectual-Disability.pdf>

<sup>3</sup> Inclusion Australia. (2020). Inclusion Australia’s Response to the issues paper on healthcare for people with cognitive disability. p. 4. Retrieved from: [https://www.inclusionaustralia.org.au/wp-content/uploads/2021/10/Our-Submissions\\_2020\\_08\\_Submission-to-the-DRC-on-healthcare-for-people-with-intellectual-disability.pdf](https://www.inclusionaustralia.org.au/wp-content/uploads/2021/10/Our-Submissions_2020_08_Submission-to-the-DRC-on-healthcare-for-people-with-intellectual-disability.pdf)

Inclusion Australia. (2020). Submission to the Disability Royal Commission – The Omnibus. p. 51-54. Retrieved from: <https://www.inclusionaustralia.org.au/submission/submission-to-the-drc-the-omnibus/>

<sup>4</sup> Troller, J., and Small, J. (2019). Health Inequality and People with Intellectual Disability—Research Summary. Retrieved from: <https://cid.org.au/wp-content/uploads/2019/07/Research-Analysis-Health-Status-of-People-With-Intellectual-Disability.pdf>

<sup>5</sup> A. Dew, L. Douse, U. Athanassiou, J. Troller, S. Reppermund. (2018). Making Mental Health Policy Inclusive of People with Intellectual Disability. University of New South Wales. [www.3dn.unsw.edu.au/sites/default/files/documents/MHID%20Policy%20Review%20Report\\_final\\_new%20template.pdf](http://www.3dn.unsw.edu.au/sites/default/files/documents/MHID%20Policy%20Review%20Report_final_new%20template.pdf);

Whittle, E. L., Fisher, K. R., Reppermund, S., & Troller, J. (2019). Access to mental health services: The experiences of people with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 32(2), 368–379. <https://doi.org/10.1111/jar.12533>

Additionally, diagnostic overshadowing is a significant barrier for people with an intellectual disability to receive appropriate support for mental ill-health. This is the tendency for medical practitioners to consider expressions of pain (including psychological pain) as ‘behaviour’ or attributable to a disability diagnosis, rather than a clinical issue requiring treatment.<sup>6</sup>

### **Lack of training among healthcare professionals**

This is a critical consequence of the widespread lack of understanding and skills of many health professionals in treating people with an intellectual disability, which contributes to the shorter life expectancy and high rates of preventable deaths among people with an intellectual disability.

Indeed, it is now well understood that training on the health of people with an intellectual disability in Australian university medical and nursing schools is very low, containing:

- A median of 2.6 hours’ compulsory content across 12 medical schools
- No intellectual disability content in 52 percent of nursing schools and very limited content overall.<sup>7</sup>

### **Higher cost of living pressures and financial hardship**

Lastly, it is well evidenced that Australians with disability face higher cost of living pressures than people without disability and are more likely to have a lower level of personal income.<sup>8</sup> People with disability also experience higher rates of poverty than those without disability.<sup>9</sup>

The National Centre for Social and Economic Modelling (NATSEM) has estimated the extra costs of living for households with a member with disability compared with households with similar characteristics but with no member with disability.<sup>10</sup> They found that:

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<sup>6</sup> K. Pouls, M. Koks-Leensen, M. Mastebroek, G. Leusink, W. Assendelft. (2022). Adults with intellectual disabilities and mental health disorders in primary care: a scoping review. *British Journal of General Practice*, 72(716): e168-e178; A. Javaid, V. Nakata, D. Michael. (2019). Diagnostic overshadowing in learning disability: think beyond the disability. *Progress in Neurology and Psychiatry*, 23(2); J. Mason, K. Scior. (2004). ‘Diagnostic Overshadowing’ Amongst Clinicians Working with People with Intellectual Disabilities in the UK. *Journal of Applied Research in Intellectual Disabilities*, 17(2): 85-90.

<sup>7</sup> Trollor, J., et al. (2016). Intellectual disability health content within medical curriculum: an audit of what our future doctors are taught. *BMC Medical Education* 16 (105):

<sup>8</sup> Australian Institute of Health and Welfare. (2022). *People with disability in Australia*. Retrieved from <https://www.aihw.gov.au/reports/disability/people-with-disability-in-australia>

<sup>9</sup> According to a report published by UNSW and the Australian Council of Social Service, 1 in 6 people with disability were living in poverty, compared with just 1 in 10 Australians without disability. See: Davidson, P., Saunders, P., Bradbury, B. and Wong, M. (2018), [Poverty in Australia 2018](#). ACOSS/UNSW Poverty and Inequality Partnership Report No. 2, Sydney: ACOSS.

<sup>10</sup> Li, J., Brown, L., La. H.N., Miranti, R., and Vidyattama, Y. (2019). *Inequalities in Standards of Living: Evidence for Improved Income Support for People with Disability*. NATSEM, Institute for Governance and Policy Analysis, University of Canberra. Report commissioned by the Australian Federation of Disability Organisations. September 2019.

- Households with an adult with profound or severe disability need an extra \$173 per week on average over and above their 2015-16 net income, and
- Households with an adult with mild or moderate disability need an extra \$87 per week on average.

In 2021, the Centre for Research Excellence in Disability and Health reported on the intersection of disability and socioeconomic hardship. In this research, more than one in three people with disability (34%) reported living in financial hardship compared to 14% of people without disability.

The same report also showed that financial hardship is associated with a two-fold increase in the experience of violence, regardless of disability status. This means people with disability who report living in financial hardship are three times as likely to experience violence than people without disability who report no financial hardship.

### **Income support for people with an intellectual disability**

Recent data from the Australian Institute of Health and Welfare (AIHW) reported that while people with disability are as likely as people without disability to have an income, that income is far more likely to come primarily from a government payment than from salary or wages.<sup>11</sup>

Among people with disability, people with an intellectual disability are among the least likely to receive an income from a wage or salary through employment: 72% of people with an intellectual disability's main source of income comes from a government pension or allowance, which for most people is the Disability Support Pension (DSP).

People with an intellectual disability report that the DSP doesn't cover the basics, such as a place to live and food on the table, let alone the additional expenses related to living with disability. In addition, any wages that people with an intellectual disability earn from employment can impact on the amount they receive from the DSP.<sup>12</sup> This means that

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<sup>11</sup> 43% or 780,000 people with disability aged 15-64 receive an income that comes primarily from government support rather than from salary or wages, compared with 7.9% or 999,000 people without disability. See: Australian Institute of Health and Welfare. (2022). *People with disability in Australia*. Retrieved from <https://www.aihw.gov.au/reports/disability/people-with-disability-in-australia>

<sup>12</sup> When people with an intellectual disability who receive the DSP earn an income, the amount of DSP they receive changes. For income over the \$190 per fortnight threshold, the DSP is reduced by 50c for each dollar earned, known as the taper rate. If a person who receives the DSP earns over \$2,243.00 per fortnight, they will receive no DSP income for that fortnight. Both the threshold and the taper rate act as a significant disincentive to work.

Services Australia (January 2023). *Income test for pensions*. Retrieved from: [www.servicesaustralia.gov.au/income-test-for-pensions?context=22276](http://www.servicesaustralia.gov.au/income-test-for-pensions?context=22276)

people with an intellectual disability live close to the poverty line, according to the latest Henderson's measure.<sup>13</sup>

## How the COVID-19 pandemic disproportionately impacted people with an intellectual disability and their families

It is well understood that people with disability, and specifically people with an intellectual disability, are at much greater risk than the general population from the COVID-19 pandemic.<sup>14</sup> This was and remains especially true for people in group residential settings, of which people with an intellectual disability—including people with very complex needs—are a high proportion.

Increased risks to people with an intellectual disability from COVID-19 are related to:

### 1. Direct health risk

People with intellectual disability:

- Have higher mortality and morbidity if infected
  - Complications from and death rates due to COVID-19 for people with intellectual and developmental disabilities (IDD) are disproportionately higher when compared to people without IDD<sup>15</sup>
- Are more likely to have the pre-existing health problems known to cause severe complications
  - Many of the risk factors that are associated with severe outcomes from COVID-19 infection, such as cardiovascular disease, diabetes and chronic lung disease are common in adults with IDD<sup>16</sup>
- Are more likely to live in congregate settings which create the conditions for widespread transmission
- Are more likely to face health discrimination
  - COVID-19 healthcare rationing is already underway internationally, and rationing rules published by overseas governments have demonstrated

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<sup>13</sup> Melbourne Institute for Applied Economic and Social Research (2022). *Poverty Lines: Australia*. Retrieved from: [Poverty-Lines-Australia-June-2022.pdf \(unimelb.edu.au\)](https://www.unimelb.edu.au/poverty-lines-australia-june-2022.pdf)

<sup>14</sup> The Institute for Health Transformation, Deakin University. 2020. Gathering the Evidence: Data on People with Intellectual Disability In Australia—A Report for Inclusion Australia. Retrieved from: [https://www.inclusionaustralia.org.au/wp-content/uploads/2021/10/Our-Submissions\\_2020\\_10\\_Submission-to-the-DRC-on-Data-on-Intellectual-Disability.pdf](https://www.inclusionaustralia.org.au/wp-content/uploads/2021/10/Our-Submissions_2020_10_Submission-to-the-DRC-on-Data-on-Intellectual-Disability.pdf)

<sup>15</sup> American Academy of Developmental Medicine and Dentistry. 2020. COVID-19 Support Guidelines White Paper. Retrieved from: <https://www.aadmd.org/white-paper>

<sup>16</sup> Ibid.

increased use of Do Not Resuscitate Orders for people with intellectual disability and limiting access to hospitals and ventilators<sup>17</sup>

- There is an underlying, pervasive and often unquestioned devaluing of people with disability that is termed 'ableism'. Given the greater risks faced by older people with disability and First Peoples with disability, when ableism intersects with ageism and/or or racism, it can result in aggravated forms of discrimination and specific human rights violations that often mean lower quality services, particularly when resources are scarce<sup>18</sup>
- The 'invisibility' of people with disability, including intellectual disability is demonstrated in the recent acknowledgement by Australia's Deputy Chief Medical Officer of the absence of consideration of people with disability in the Federal Government's initial COVID-19 Pandemic planning and in the fact that the Commonwealth Department of Health lacks an area with responsibility for the health of people with disabilities.<sup>19</sup>

## 2. Disability workforce issues

- The National Disability Services' Australian Disability Workforce Report (February 2018)<sup>20</sup> highlighted that the disability workforce had a large and growing casual workforce compared to other industries, resulting in high turnover and increased quality risks.
- The report, which was written pre-COVID-19, confirms the distinctive character of the disability workforce: a majority female, mainly part-time group of workers, over two-fifths of whom are casually employed.
- The report advocated for increased funding to support high-quality jobs, which would allow the sector to retain a skilled and experienced workforce.
- The casual nature of the workforce in aged care settings has been acknowledged as a significant risk vector for COVID-19 as it has meant that workers often need to work across multiple facilities to earn a living wage.
- Between May and June 2020, the Centre for Health Equity at Melbourne University conducted a national online survey of Disability Support Workers (DSWs). The

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<sup>17</sup> Hellman, D. 2020. 'Doctors facing grim choice over ventilators told to put patients with disabilities at the back of the line'. *The Conversation*. Retrieved from: <https://theconversation.com/doctors-facing-grim-choice-over-ventilators-told-to-put-patients-with-disabilities-at-the-back-of-the-line-134884>

<sup>18</sup> Statement of Concern: COVID-19: Human rights, disability and ethical decision-making. Retrieved from: [https://dpoa.org.au/wp-content/uploads/2020/04/Statement-of-Concern-COVID-19-Human-rights-disability-and-ethical-decision-making\\_Final.pdf](https://dpoa.org.au/wp-content/uploads/2020/04/Statement-of-Concern-COVID-19-Human-rights-disability-and-ethical-decision-making_Final.pdf)

<sup>19</sup> Collins, A. 2020. 'Health bureaucrat tells royal commission people with disabilities not mentioned in coronavirus plan'. *ABC News*. Retrieved from: <https://www.abc.net.au/news/2020-08-21/people-with-disability-not-mentioned-government-covid-19-plan/12581858>

<sup>20</sup> National Disability Services. 2018. Australian Disability Workforce Report. Retrieved from: <https://www.nds.org.au/policy-library/australian-disability-workforce-report-second-edition-highlights-workforce-risks1>

results, as summarised in a report titled Disability Support Workers: The Forgotten Workforce in COVID-19,<sup>21</sup> found that of DSWs:

- 53% provided support with tasks that require close personal contact like feeding and brushing teeth
- 23% had not received any COVID-19 infection control training
- Of the 77% who did receive training, 48% would like more
- 64% had received or purchased some form of personal protection equipment (PPE). More than half (54%) received gloves and 37% masks from their employer. Notably, 38% purchased their own masks
- 23% had been tested for COVID-19 infection and 11% wanted to be tested
- 14% worked for more than one provider and six per cent worked in both the aged-care and disability sector
- 30% worked in two or more settings, and 14% worked in three or more settings
- 27% cancelled shifts because they were worried about COVID-19 infection and 35% had shifts cancelled by clients or employers due to fear of COVID-19
- 16% reported high psychological distress levels consistent with serious probable mental illness; 22% of workers experiencing financial stress had probable mental illness, compared to 14% among those who did not report financial problems.
- The researchers made a number of recommendations, including:
  - updating PPE guidelines
  - proactively reaching out to DSWs so they can receive the required training
  - ensuring they have access to pandemic leave
  - making sure expert health staff can provide back-up if needed.

### **3. Lack of coordination between state, territory and federal governments**

- Our community's experience was that people with disability—and especially people with an intellectual disability—were not recognised or sufficiently including in the Commonwealth Government's public messaging about the COVID-19 pandemic or the response. While the needs and experiences of people with disability were discussed by state first ministers, we did not hear this community being acknowledged by the Prime Minister during his press conferences, and our community was not consulted in any meaningful way about their experiences and the solutions needed.

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<sup>21</sup> University of Melbourne. 2020. Disability Support Workers: The Forgotten Workforce in COVID-19. Retrieved from: <https://mbspgh.unimelb.edu.au/centres-institutes/centre-for-health-equity/about-us/forgotten-workforce-in-covid-19>

- As such, the pandemic starkly demonstrated how little governments—at every level—knew about the experiences, needs and rights of people with disability.
- Key among these ‘unknowns’ was where people with an intellectual disability were physically living and how they could be reached in an emergency. By and large, the government had no way of communicating with this cohort.
- We know that many people with an intellectual disability live in group homes run by large service providers: if those providers were registered under the NDIS, then the government had a means of communication. However, government had no way of reaching people living in unregistered Supported Independent Living (SIL) arrangements or other informal housing arrangements like boarding houses.
- This meant that one of the only ways for governments to communicate was via state guardians (for those under guardianship orders). It emerged that for many people this meant communication by post only, which meant weeks before people could receive and respond to communications.
- There was no alternative mechanism devised by government to communicate effectively (not least in accessible formats) with people with an intellectual disability (see #5 below).
- Noting the recently released recommendations from the NDIS Review—particularly Recommendation 17 in relation to the new model for the regulation of providers<sup>22</sup>—we recommend baseline enrolment (including ABN and registered address) for all organisations providing services funded by the NDIS. This is an important safety measure and risk mitigation measure in the event of other emergencies. We note this recommendation is controversial in the disability community and believe that any further decisions about registration and enrolment practices (other than baseline enrolment) should be developed through a thorough co-design process with Disability Representative Organisations.
- The rollout of the NDIS across Australia created problems with locating the boundaries of responsibility between the different levels of government. These difficulties arose because:
  - Aged care and disability services have been treated differently by governments despite having similar funding, health and housing profiles and risks;
  - Pre-NDIS, state governments were the disability service provider of last resort for people with intellectual disabilities and took responsibility for ensuring access to health, housing and support. During the pandemic, it was

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<sup>22</sup> NDIS Review. 2023. Working together to deliver the NDIS: Independent Review into the National Disability Insurance Scheme. Retrieved from: <https://www.ndisreview.gov.au/sites/default/files/resource/download/working-together-ndis-review-final-report.pdf>. Pages 215-217.

unclear who is accountable for emergency disability support worker assistance in a pandemic; and

- In the absence of clearly articulated and considered government guidelines, service providers were left to make critical decisions on behalf of people with intellectual disabilities, placing both individuals and service providers at risk.

#### **4. The increased risk of human rights breaches during the pandemic**

- The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), which was ratified by Australia in 2008, affirms that people with disability are entitled to the human rights due all human beings on an equal basis.
- The UNCRPD states that people with disability should enjoy the highest attainable standard of health, and be provided with health care and health services without discrimination.
- The UNCRPD also outlines that health care should be provided on the basis of free and informed consent, and there should be no discriminatory denial of health care, health services and food or fluids on the basis of impairment.
- During the pandemic, we expressed concern that supported decision-making for health choices and access to services as a result of COVID-19 arrangements has become non-existent for many people with intellectual disability.
- We were especially concerned that disability services were making decisions on behalf of people who do not have family or access to other advocacy support.
- During the pandemic, we also heard that many disability services were justifying restrictive practices, such as limiting visitors, outings and participation in other activities under the guise of precautionary welfare measures.
- There was a lack of oversight required to ensure any such decisions are necessary, lawful, and not in breach of human rights legislation.
- We also raised concerns that any such restrictive practices put into place in the name of pandemic protection may outlast the current pandemic and mean people with intellectual disability are denied their rights to enjoy the same freedoms, choices and quality of life as other Australians.

#### **5. Lack of accessible information and access to supported decision-making for people with an intellectual disability**

- People with an intellectual disability have a much lower level of health literacy compared to the general population.<sup>23</sup> This is especially true for people with

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<sup>23</sup> Nils Sebastian Vetter et al. (2021). Promoting health literacy in people with intellectual disabilities via explanatory videos: scoping reviews, *Health Promotion International* 193, <https://doi.org/10.1093/heapro/daab193>

complex communication support needs, such as those who communicate in ways other than speaking.

- An abundance of Australian and international research has demonstrated that health literacy is an important predictor of health status, and low health literacy is associated with poorer health outcomes.<sup>24</sup>
- Respectful and inclusive communication and information is a basic requirement for genuine informed consent to be provided by anyone receiving any kind of healthcare. It should be a basic expectation of all healthcare staff when treating people with an intellectual disability.
- One pathway to providing informed consent is through Supported Decision Making. Under Articles 3 and 4 and, more recently, Article 12 of the UNCRPD, which is about equal recognition before the law,<sup>25</sup> all people have rights to make their own decisions, including the decision to change their mind.
- Supported decision-making is a way of thinking and relating to others that respects peoples' rights to make their own decisions—it assumes all people have the capacity to make their own decisions to the maximum extent possible.
- Yet the rights of people with an intellectual disability to make their own decisions is often ignored by medical professionals. For example, people with an intellectual disability reported being ignored by medical professional and have their family members or support workers expected to speak for them.<sup>26</sup> It is common for information to be withheld from people with an intellectual disability based on the discriminatory assumption—whether intentional or not—that a person does not have the capacity to understand what a procedure involves or what kind of treatment options are available to them, and that they cannot make their own decisions or give informed consent.<sup>27</sup>
- Further, Inclusion Australia was a member of the **Department of Health COVID Comms Working Group** throughout and beyond the pandemic.
- In that group, we consistently called for more accessible materials but unfortunately found that progress on creating and disseminating those materials was either very slow or did not happen at all.
- The Easy Read documents that were made available tended to be published long after the originals were made available. They were then very hard to find on the Department of Health website.

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<sup>24</sup> Skes, M., et al. (2020). Health Literacy regarding people with intellectual disability “Our right to a healthier future.” *European Journal of Public Health*, 30(Supplement\_5). <https://doi.org/10.1093/eurpub/ckaa166.473>

<sup>25</sup> Article 12 – Equal recognition before the law. *United Nations Convention on the Rights of People with Disabilities*. Retrieved from: [Article 12 – Equal recognition before the law | United Nations Enable](https://www.un.org/disabilities/convention/convention_full.asp)

<sup>26</sup> Inclusion Australia. (2020). Submission to the Disability Royal Commission – The Omnibus. p. 51-54. Retrieved from: <https://www.inclusionaustralia.org.au/submission/submission-to-the-drc-the-omnibus/>

<sup>27</sup> Inclusion Australia. (2020). Submission to the Disability Royal Commission – The Omnibus. Retrieved from: <https://www.inclusionaustralia.org.au/submission/submission-to-the-drc-the-omnibus/>

- We also recommended the Department of Health develop short films such as our [Living with COVID animation](#) (which was funded through philanthropy). Topics suggested included:
  - the fear of medical appointments / managing needle-phobia
  - significant past traumas and anxieties people with an intellectual disability and families have within the health system over a lifetime of inaccessible services or traumatic experiences.
  - the increase in restrictive practices in group homes when COVID-19 was present
  - what happens if you contract COVID-19.
- This idea was not taken up by the Department, who instead developed a video featuring people with a range of disabilities but which was not representative of the specific issues people with an intellectual disability were facing (and which continue to be relevant).
- We believe that this was a significant gap in the Commonwealth’s COVID-19 response, in terms of the provision of accessible information and recognition of the unique needs of people with an intellectual disability, as a subset of people with disability. This is part of a broader dedifferentiation approach by government which contributes to the ongoing invisibility of people with an intellectual disability and to the subsequent development of ineffective policy and practice.<sup>28</sup>

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<sup>28</sup> Bigby notes that: ‘For people with intellectual disabilities, dedifferentiation emphasises each individual’s needs and functional abilities and their membership of the generic group “people with disabilities,” rather than the impairment-specific group “people with intellectual disabilities.”’ Bigby. (2020). Dedifferentiation and people with intellectual disabilities in the Australian National Disability Insurance Scheme: Bringing research, politics and policy together. *Journal of Intellectual and Developmental Disability*. DOI: 10.3109/13668250.2020.1776852.