



2 June 2023

## Re: Mid-term review of the National Health Reform Agreement Addendum 2020-25

Dear Rosemary Huxtable PSM and Michael Walsh PSM,

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. We have teams in Victoria, Western Australia, and the Northern Territory, and we have member organisations in New South Wales, Queensland, South Australia, Tasmania, Victoria and Western Australia.

Thank you for the opportunity to provide feedback on the mid-term review of the National Health Reform Agreement (NHRA) Addendum 2020-25, and particularly for granting us extra time to finalise our response.

We greatly appreciate your flexibility and hope our contribution is valuable in highlighting some of the important principles and long-term reforms within the NHRA Addendum 2020-25 that hold significant consequences for the lives of people with an intellectual disability and their family members who we represent.

### **A note on accessibility**

Given that overall health outcomes and access to healthcare services are significant issues for our community, we wish to note that it would be very valuable to have a summary of the NHRA Addendum 2020-25 available in a Plain Language format, or ideally Easy Read.

This would ensure that our community can access, be informed about, and engage with, the important agreements and reform agendas contained within the NHRA Addendum 2020-25, many of which have significant consequences for the lives of people with an intellectual disability and their family members.

We also ask that, when public, the report to Health Ministers be translated into Plain Language, or ideally Easy Read, so that our community can engage with its findings and understand how any reforms may impact their experiences of engaging with healthcare services in the future. This would also help to actualise the ethic and principle of 'nothing about us without us' by including people with an intellectual disability and inviting them to engage in matters that affect them.

We sincerely thank the independent co-leads in advance for this, and warmly invite any further conversations on how to implement these inclusive practices if that would be useful.

## Background to our response to the mid-term review of the NHRA Addendum 2020-25

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—that are inclusive and meet their needs, including:

- 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
- 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>

As a result of the lack of inclusivity within healthcare services, 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 specifically—which we note comprises an important aspect of the NHRA Addendum 2020-25—it is estimated that more than half (57%) of people with an intellectual

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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>

<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/>

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>

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> 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>

While we note the current mid-term review is focussed on the operation of the NHRA Addendum 2020-25, and not the health system in entirety, we feel it is important to highlight this context given what it reveals about the severity of what many people with an intellectual disability and their family members experience in the Australian healthcare system.

Given this, we strongly believe that any agreement making for reform by Commonwealth and state and territory parties must account for the tremendous inequity people with an intellectual disability experience. It must also acknowledge the specific and increasing body of evidence-based interventions and reforms that are urgently required, as described in the following section.

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<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>

<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> Troller, 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):

We draw attention to these issues as background to our responses below, which highlight how the NHRA Addendum 2020-25 could be improved to better reflect the needs of people with an intellectual disability, as well as supporting the Australian healthcare system to meet its obligations under *Article 25—Health* of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD).

## **Response to the mid-term review of the NHRA Addendum 2020-25**

Our first recommendation emerges from the context set out above, which demonstrates the many interconnected ways in which the healthcare system is failing people with an intellectual disability.

Given this, we wish to recommend:

**The independent reviewers must consider how the NHRA Addendum 2020-25 could specifically outline the ways its principles and objectives could impact and improve the experiences of people with an intellectual disability, and this must be included with resultant recommendations in the final report to Ministers.**

We believe this would strengthen the NHRA Addendum 2020-25 by better targeting its objectives, and indeed, to help it to achieve its mandate to improve patient outcomes, patient experience and access to services, including by focussing on what matters most to patients (page 7 of the Addendum). It would also help bring it into alignment with the National Roadmap for Improving the Health of People with Intellectual Disability (the Roadmap),<sup>8</sup> which is an Associated Plan to *Australia's Disability Strategy 2021-2031*.<sup>9</sup> The Roadmap aims to, among other things:

- Improve support for people with an intellectual disability and their families
- Develop better models of care for people with intellectual disability
- Provide support for health professionals to help them deliver quality care for people with an intellectual disability.

We also wish to comment on two aspects of the implementation of the long-term reforms (Schedule C) within the NHRA Addendum 2020-25.

These present significant opportunities to promote better outcomes for people with an intellectual disability and their family members. Our responses should be considered in relation to the context set out above.

### **Empowering people through health literacy**

We strongly agree that prioritising prevention and helping people manage their health across their lifetime is a critical measure to improve preventative healthcare, especially through empowering people through health literacy.

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<sup>8</sup> National Roadmap for Improving the Health of People with Intellectual Disability. 2021. Department of Health and Aged Care. Retrieved from: <https://www.health.gov.au/our-work/national-roadmap-for-improving-the-health-of-people-with-intellectual-disability>

<sup>9</sup> Australia's Disability Strategy 2021-2031. Retrieved from: <https://www.disabilitygateway.gov.au/document/3106>

When examining the long-term health reform principles (Schedule C of the Addendum), it is important for the independent reviewers to consider the following:

- People with an intellectual disability have a much lower level of health literacy compared to the general population<sup>10</sup>
- This is especially true for people with complex communication support needs, such as those who communicate in ways other than speaking
- There is an abundance of Australian and international research that has demonstrated that health literacy is an important predictor of health status, and low health literacy is associated with poorer health outcomes.<sup>11</sup>

Given the overall poorer health outcomes currently experienced by people with an intellectual disability highlighted above, we believe it is critical that the NHRA Addendum 2020-25 better target this long-term health reform by:

- Specifically acknowledging the gaps within health literacy among people with an intellectual disability and recognise the systemic barriers people with an intellectual disability face when trying to access health promotion materials
  - By and large, these barriers relate to the inaccessibility of health literacy materials and the general lack of resources co-designed and delivered by people with an intellectual disability
- Make provisions for ongoing resourcing of inclusive practices in the promotion of health literacy at state and territory levels, such as ensuring health promotion materials are available in Easy Read, have been co-designed and delivered by people with an intellectual disability and family members, and that they align with evidence-based practices that are now emerging in the research.<sup>12</sup>

### **Driving safe, high-quality care in the right place at the right time**

Another aspect that we wish to highlight is the need to consider how accessible information and inclusive communication within healthcare services can help “drive safe, high-quality care in the right place at the right time” (page 56 of the Addendum), especially by creating a pathway for people

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<sup>10</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>

<sup>11</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>12</sup> For example, see: 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>; Latteck, Ä.-D., & Bruland, D. (2020). Inclusion of People with Intellectual Disabilities in Health Literacy: Lessons Learned from Three Participative Projects for Future Initiatives. *International Journal of Environmental Research and Public Health*, 17(7), 2455–. <https://doi.org/10.3390/ijerph17072455>; and Chinn, D. (2017). Review of Interventions to Enhance the Health Communication of People with Intellectual Disabilities: A communicative Health Literacy Perspective. *Journal of Applied Research in Intellectual Disabilities* 30. 345-359.

with an intellectual disability to be able to provide genuine informed consent when accessing healthcare.

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 Article 3, Article 4 and, more recently, Article 12 of the UNCRPD, which is about equal recognition before the law,<sup>13</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 there is a lot of academic and lived experience evidence that 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>14</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>15</sup>

Therefore, we recommend that the independent reviewers take this important legislative background regarding decision-making and consent into consideration when examining the long-term health reform principles, and make provisions for these basic human rights to be embedded within the long-term health reforms of the NHRA Addendum 2020-25.

## Summary

In conclusion, we wish to recommend to the independent reviewers that:

1. The NHRA Addendum 2020-25 specifically acknowledges and outlines the ways its principles and long-term reforms could impact and improve the experiences of people with an intellectual disability and include this in their final report to Ministers.
2. Design a long-term health reform that specifically acknowledges the gaps within health literacy among people with an intellectual disability and recognises the systemic barriers people with an intellectual disability face when trying to access health promotion materials as a pathway to improving preventative health and wellbeing. The related recommendation is to embed an

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<sup>13</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](#)

<sup>14</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>15</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/>

agreement to sustainably fund states and territories to produce health promotion materials in inclusive formats that have been designed and are delivered by people with an intellectual disability.

3. Consider the legislative background set out in the United Nations Convention on the Rights of Persons with Disabilities regarding access to health, informed consent and decision-making when examining the long-term health reform principles. Embed these basic human rights to informed consent and decision-making within the long-term health reforms of the NHRA Addendum 2020-25.

We warmly thank the independent reviewers for the opportunity to provide a response to the mid-term review of the National Health Reform Agreement Addendum 2020-25, and for allowing us extra time to make our submission.

We invite any further opportunities to consult on any of the issues raised in this letter.

Kind regards,



**Catherine McAlpine**  
Chief Executive Officer