



12 May 2023

**Re: Australian Commission of Safety and Quality in Healthcare—Inclusive consultation for the Psychotropic Medicines in Cognitive Disability or Impairment Clinical Care Standard**

Dear Commissioner,

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.

We thank the Commission for the opportunity to provide feedback on the Draft Psychotropic Medicines in Cognitive Disability or Impairment Clinical Care Standard. We welcome any further opportunities to consult on specific issues raised in this letter.

**A note on terminology**

The Commission uses the term ‘Cognitive Disability or Impairment’, which is an umbrella term that describes the effects of several conditions, such as acquired brain injury, stroke, intellectual disability, dementia, and foetal alcohol spectrum disorder.<sup>1</sup> Cognitive Disability or Impairment may be temporary or permanent.

Intellectual disability, in contrast to Cognitive Disability or Impairment, specifically describes a lifelong condition which affects a person’s intellectual skills and behaviour in different situations. It is usually diagnosed in early childhood.

Intellectual disability can affect a person in many ways, including memory, understanding, communication, problem-solving, self-care, social and emotional skills, and physical skills.

Every person with an intellectual disability is different, and everyone has a unique story to tell.

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<sup>1</sup> p. 60 of consultation draft clinical care standards

## Key Recommendations

### **1: Provide rights-based training for healthcare staff.**

Implement rights-based training for all relevant health professionals as a standard of care. Training should cover the human rights and equal value of people with an intellectual disability, the identification of intellectual disability, communicating with people with an intellectual disability, and adjustments to clinical care practice in response to support needs. Training should be trauma-informed and co-designed and delivered by people with an intellectual disability and family members.

### **2: Support communication needs.**

Make an addition to Clinical Care Standard 2 outlining the need to support a person's communication style and support needs, including by making Alternative and Augmented Communication (AAC) tools accessible when providing information about the relevant psychotropic medicine and obtaining informed consent. Make an addition that says all people must have access to information in a way that makes sense to them and must be given opportunity to provide consent at every stage of their care.

### **3: Provide everyone with access to Supported Decision Making**

Clinical Care Standard 2 should be re-written to remove the reference to Supported Decision Making being conditional on a judgement of a person's 'decision-making capacity' and replaced with a standard that says all people must have access to Supported Decision Making at every stage of their care to the maximum extent possible, including as a rights-based, accessible way to provide genuinely informed consent and make choices about when to stop a psychotropic medicine.

### **4: Increase accessibility of information sharing and communication.**

Make an addition to Clinical Care Standard 8 that says information about a person's ongoing healthcare needs must be communicated in an accessible way by using Plain Language, Easy Read and/or AAC for those with complex communication needs. This needs to be provided at every stage of a person's care and at every transfer of care.

## Response to Consultation Questions

Our responses to the consultation questions below have been drawn from our previous advocacy in access to healthcare,<sup>2</sup> and current evidence for best practice in Supported Decision Making. We also draw on the collective expertise of Inclusion Australia's Services for One<sup>3</sup> Community of Practice, which includes family members and other supporters of people with an intellectual disability, including those who have used psychotropic medications.

Our responses also reflect the legislative setting in relation to the provision of healthcare in Australia. Article 25 of the *United Nations Convention on the Rights of Persons with Disability* (UNCRPD) recognises the right to the highest attainable standard of health without discrimination on the basis of disability.

The right to health does not just mean the right to 'be healthy': it contains several important entitlements and freedoms, which include but are not limited to:

- Non-discrimination
- Control over your own health and body
- Free and informed consent
- Freedom from non-consensual medical treatment

The other important policy setting is the National Roadmap for Improving the Health of People with Intellectual Disability (the Roadmap),<sup>4</sup> which is an Associated Plan to *Australia's Disability Strategy 2021-2031*.<sup>5</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.

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<sup>2</sup> For more of our previous work, please see the following submissions:

**Submission to the Disability Royal Commission on healthcare for people with an intellectual disability:**

<https://www.inclusionaustralia.org.au/submission/submission-to-the-drc-on-healthcare-for-people-with-intellectual-disability/>

**Submission on the Draft National Stigma and Discrimination Reduction Strategy:**

<https://www.inclusionaustralia.org.au/submission/draft-national-stigma-and-discrimination-reduction-strategy/>

**Inclusion Australia's Response to the issues paper on healthcare for people with cognitive disability**

[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)

<sup>3</sup> For more information on Services for One, please see: <https://www.inclusionaustralia.org.au/services-for-one-project/>

<sup>4</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>5</sup> Australia's Disability Strategy 2021-2031. Retrieved from: <https://www.disabilitygateway.gov.au/document/3106>

In particular, the Roadmap has a strong focus on strengthening the communication between health professionals and people with an intellectual disability, as well as providing person-centred and trauma-informed models of care.

These legislative and policy settings also form the background to our recommendations.

This section addresses the following consultation questions:

1) Does the quality statement adequately describe the quality of care that should be provided?

1 a) How could the quality statement be improved?

Below, we provide recommendations for improvement to **Clinical Care Standards 1, 2 and 8**.

## 1. Person- and family-centred care

We agree it is critical that a person receives healthcare that is driven by their individual preferences, needs and values, and upholds their personal dignity, and human and legal rights.

**One way to provide assurance that people will receive this standard of care is to ensure healthcare professionals and other relevant staff receive training in understanding intellectual disability.**

Training on the health of people with an intellectual disability in 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>6</sup>

People with an intellectual disability, their family members and other supporters have told us that their experience in healthcare systems is often negative. It is common for people with an intellectual disability to be ignored, and their family members are often expected to speak for them.<sup>7</sup>

The behaviour of some medical professionals towards people with an intellectual disability points to a chronic lack of training, as well as, at times, an assumption that people with an intellectual disability cannot give consent.<sup>8</sup>

Research demonstrates that the skills and focus of healthcare services for people with an intellectual disability needs considerable enhancement overall.<sup>9</sup> Rights-based training should be provided to all

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<sup>6</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>7</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>8</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)

<sup>9</sup> In 2019, Inclusion Australia joined with other Disability Representative Organisations to propose a national program focused on the enhancement of health care to people with an intellectual disability by GPs and other primary health care services. For more detail on this proposal, which was launched as part of the Our Health

healthcare staff, particularly those involved with the care of people using a psychotropic medication, to raise the standard of care people with an intellectual disability and their family members receive. This will, over time, help to shift the negative attitudes towards people with an intellectual disability that continue to pervade many aspects of Australian society, including healthcare.

Rights-based training should be delivered by people with an intellectual disability and family members. It should be trauma-informed and culturally responsive. It should cover:

- the health of people with an intellectual disability and the significant inequalities that people with an intellectual experience in accessing healthcare
- the equal value of people with an intellectual disability
- the challenges that may arise in communication between people with an intellectual disability and health professionals
- the identification of intellectual disability, including people who may not identify as having an intellectual disability, but who have similar support needs.

Explicitly recognising the need for, and a commitment to providing, rights-based training within this standard of care will help to ensure healthcare professionals can provide services that are genuinely person- and family-centred.

**Recommendation 1: Provide rights-based training for healthcare staff.**

Implement rights-based training for all relevant health professionals as a standard of care. Training should cover the human rights and equal value of people with an intellectual disability, the identification of intellectual disability, communicating with people with an intellectual disability, and adjustments to clinical care practice in response to support needs. Training should be trauma-informed and co-designed and delivered by people with an intellectual disability and family members.

## **2. Informed consent for psychotropic medicine**

There are two important points of improvement that we recommend being made to this Clinical Care Standard.

### **i. Communication needs and informed consent**

We agree that if a psychotropic medicine is being considered, the person and their family (or other supporters) should be informed about the reason for prescribing, and its potential benefits and harms. Informed consent should then be obtained and documented before use, **as well as during monitoring and when considering stopping the use of a medication.**

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Counts – End Deadly Disability Discrimination Campaign, please see the Campaign website: <https://cid.org.au/our-campaigns/our-health-counts/>

There is a tendency for the provision of consent to only be considered at the beginning of a person's care and use of psychotropic medication. However, consent is something that must be considered at every stage of a person's care, especially in relation to decisions about stopping use of a psychotropic medication.

This is because the use of psychotropic medication is a restrictive practice. As such, all aspects of its use must be considered under the relevant legislative context.

The legislative context is set by the *NDIS Act 2013*, which gives effect to Australia's obligations under the United Nations Convention on the Rights of Persons with Disability (UNCRPD). Given that restrictive practices can present serious human rights breaches—which people with an intellectual disability are most at risk of experiencing<sup>10</sup>—the legislative setting stipulates the **reduction** and **elimination** of restrictive practices over time.

So, people with an intellectual disability and their family members have a **right** under this legislative setting to be informed in a way **that makes sense to them** at every stage of their care, so they can provide **informed consent** not only to commence the use of a psychotropic medication, but to continue and/or cease that use.

However, when seeking informed consent at each of these steps, healthcare professionals must be **aware of and responsive to the person's communication needs**, particularly where a person may have complex communication support needs.

It is important for healthcare professionals to be aware that some people may not be able to give verbal or written consent but still **have the right to be informed and decide** for themselves, with appropriate support, whether or not to consent to each and all stages of their care.

As such, we strongly recommend that this Clinical Care Standard make provisions for those who have complex communication support needs and who may use Alternative and Augmented Communication (AAC), so that they can access the information given to them about their prescription and associated benefits and harms, as well as have the opportunity to provide consent in a way that is accessible to them.

There may still be people who cannot consent at all. However, their rights to Supported Decision Making must still be upheld. This is discussed in the following section.

### **Recommendation 2: Support communication needs**

Make an addition to Clinical Care Standard 2 outlining the need to support a person's communication style and support needs, including by making Alternative and Augmented Communication (AAC) tools accessible when providing information about the relevant psychotropic medicine and obtaining informed consent. Make an addition that says all people must have access to information in a way that makes sense to them and must be given opportunity to provide consent at every stage of their care.

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<sup>10</sup> Clark, L.L., Hext, G. and Xyrichis, A. (2018), "Beyond restraint: raising awareness of restrictive practices in acute care settings", *International Journal of Nursing Studies*, Vol. 86, doi:10.1016/j.ijnurstu.2018.06.006.

## ii. Access to Supported Decision Making

We are concerned with the following aspect of Clinical Care Standard 2, which notes:

*If the person's decision-making capacity is impaired, processes for supported decision making, proxy consent or exemptions under relevant legislation are followed as appropriate.*

There are two main issues here. The first is to do with the notion of 'decision-making capacity', the second is to do with Supported Decision Making being put forward as conditional.

Current evidence and best-practice in Supported Decision Making—reflecting Article 12 of the UNCRPD, which is about equal recognition before the law<sup>11</sup>—is very clear that **all people have the right to make decisions**. It follows that all people have the **capacity** to make decisions.

In other words, decision-making capacity is not a circumstance that may or may not be "impaired", as this Clinical Care Standard suggests. Rather, decision-making capacity is a universal quality that **all people possess**, regardless of their disability, communication style, or other life circumstances.

Although we do not believe this is the intention, the wording of this Clinical Care Standard is problematic because it frames decision-making capacity as something that a person may not possess. This does not reflect international law—to which Australia is bound—or current evidence.

As a result, this Clinical Care Standard frames Supported Decision Making as something that will only be *conditionally provided* based on a misguided understanding of 'decision-making capacity'.

However, Supported Decision Making is something **all people have the right to** and therefore must have access to at every step of their care: when they are considering starting a medication as well as during that use, and when they may be considering stopping a medication.

Supported Decision Making must therefore be embedded in this Clinical Care Standard so all people with an intellectual disability can access it when deciding whether or not to consent at every step of their care regarding use of psychotropic medication.<sup>12</sup>

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<sup>11</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>12</sup> There is an increasing abundance of free, publicly available Supported Decision Making resources, many of which have been codesigned with people with an intellectual disability, for both decision-makers and decision-supporters. As part of Inclusion Australia's recent Supported Decision Making project *Make Decisions Real*, which was led by people with an intellectual disability, the project team launched a comprehensive Resource Directory bringing together Supported Decision Making resources from across Australia. View the Resource Directory here: <https://www.inclusionaustralia.org.au/resource/supported-decision-making-resource-directory/>

The NSW Council for Intellectual Disability (CID) is running a Supported Decision Making project called My Rights Matter. The project's online hub contains a number of Supported decision making resources and stories from people with an intellectual disability about Supported decision making: <https://cid.org.au/issues/my-rights-matter/>

Further, decision-making is a skill that can be learned. As such, Supported Decision Making *enables* capacity to be built with the right supports. This is why it is critical—as well as being a human right protected by Australia’s obligations under the UNCRPD—that all people have access to Supported Decision Making when making decisions about their health, or any other part of life.<sup>13</sup>

**Recommendation 3: Provide everyone with access to Supported Decision Making**

Clinical Care Standard 2 should be re-written to remove the reference to Supported Decision Making being conditional on a judgement of a person’s ‘decision-making capacity’ and replaced with a standard that says all people must have access to Supported Decision Making at every stage of their care to the maximum extent possible, including as a rights-based, accessible way to provide genuinely informed consent and make choices about when to stop a psychotropic medicine.

An additional point we wish to make regarding the Easy Read version of the Consultation draft is about clarity of terms and definitions. On page 11 of the Easy Read document, there is reference to “shared decision making” in the section about informed consent.

This wording is confusing, since the Clinical Care Standards refer to “Supported Decision Making”, which is what most people with an intellectual disability and their supporters would be used to as a term to describe getting support to make decisions. Yet, the Easy Read document describes “shared decision making” as how “a person decides if they want to take psychotropic medicines”.

This is misleading, because “shared decision making” usually refers to Guardianship or other forms of substitute decision making, which is what the Easy Read version goes on to describe. It does not mention Supported Decision Making at all.

While we are glad to see there is an Easy Read version of the Clinical Care Standards available, we strongly suggest that there is consistency around the term ‘Supported Decision Making’ to ensure there is confluence between documents.

With reference to Recommendation 3 above, the Easy Read document should also be rewritten to reflect the fact that all people must have access to Supported Decision Making through the Clinical Care Standards.

### **3. Information sharing and communication at transfers of care**

Often, information produced by healthcare professionals is written at a reading level above that of the people who need to access that information, including people with an intellectual disability, as

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<sup>13</sup> For more information on Inclusion Australia’s advocacy for Supported Decision Making, please see our submission to the NDIA on Support for Decision Making: <https://www.inclusionaustralia.org.au/submission/submission-to-the-ndia-on-support-for-decision-making/>



well as their family members, including parents with an intellectual disability, and other supporters.

14

When providing information about a person’s ongoing needs during the transfer of a person’s healthcare, **the information must be accessible to the person, their supporters, and other relevant staff.**

Having accessible information also enables access to Supported Decision Making and provides a better guarantee that informed consent can be genuinely received from the person.

This means providing information to a person in a way that makes sense to them, such as in Easy Read or Plain Language materials, or with use of AAC. It also means giving people enough time to make sense of and reflect on the information.

Further, providing accessible information that can be used by a number of people involved in a person’s care will allow for more seamless interfacing between healthcare practitioners and departments—particularly in what can often be a complex and administratively challenging system for people with an intellectual disability and their families to navigate.

This recommendation will also support Clinical Care Standard 1 by ensuring the person’s care is genuinely person- and family-centred.

**Recommendation 4: Increase accessibility of information sharing and communication**

Make an addition to Clinical Care Standard 8 that says information about a person’s ongoing healthcare needs must be communicated in an accessible way by using Plain Language, Easy Read and/or AAC for those with complex communication needs. This needs to be provided at every stage of a person’s care and at every transfer of care.

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<sup>14</sup> Adkins, A. D., & Singh, N. N. (2001). Reading level and readability of patient education materials in mental health. *Journal of Child and Family Studies*, 10, 1–8. doi:10.1023/A:1016617115729

McKeegan, G. F., Laneir, A. E., Adkins, A. D., Amato, J. L., Elkins, E. L., & Lugar, S. B. (2002). Reading grade level and readability of behavior treatment programs for individuals with disabilities. *Behavior Therapist*, 25, 169–171.

Wardale, S., Davis, F., Vassos, M., and Nankervis, K. (2018). The outcome of a statewide audit of the quality of positive behaviour support plans. *Journal of intellectual & developmental disability*, 43 (2), p.202-212

We thank the Australian Commission on Safety and Quality in Healthcare for the opportunity to provide this submission of feedback on the Draft Psychotropic Medicines in Cognitive Disability or Impairment Clinical Care Standard.

We welcome any further opportunities to consult on specific issues raised in this letter in the future.

Kind regards,

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

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