National Centre of Excellence in Intellectual Disability Health

Conjoint Professor Anne Duggan
Chief Executive Officer
Australian Commission on Safety and Quality in Health Care

By email: comm4safety.compcare@safetyandquality.gov.au

5 September 2025

Dear Professor Duggan,

Submission On Draft Revised Open Disclosure Framework

We write on behalf of the National Centre of Excellence in Intellectual Disability Health to provide input on the Draft Revised Open Disclosure Framework. We appreciate the opportunity to comment.

In our submission we provide key recommendations to improve the draft so that it better addresses the rights and needs of people with intellectual disability. Our recommendations should also be helpful in relation to people with other cognitive and mental health impairments.

Since the rationale for many of our suggestions comes from the interplay of a number of common factors, we are providing feedback via this letter rather than your form.

We trust you will find this information useful in the development of the Revised Open Disclosure Framework. We would welcome the opportunity to discuss our comments further and should you require further information about this submission, please do not hesitate to contact Jim Simpson on 0418 635 630 or at jim@cid.org.au.

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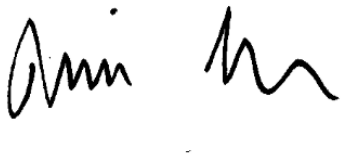
National Centre of Excellence in Intellectual Disability Health

Sincerely,



Jim Simpson AO
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In conjunction with:

Kitty Rose Foley
Team Lead, Health Services Development
National Centre of Excellence in Intellectual Disability Health

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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National Centre of Excellence in Intellectual Disability Health

SUBMISSION

Executive Summary

People with intellectual disability face stark health and mental health inequalities and multiple barriers to accessing health care that meets their needs. The Disability Royal Commission found that 'people with cognitive disability have been and continue to be subject to systemic neglect in the Australian health system'.[1] Alarmingly, people with intellectual disability are twice as likely as other people to die from potentially avoidable causes.

The key open disclosure issues from our perspective are:

- Ensuring that people with intellectual disability receive adjustments and supports to maximise their opportunities to fully participate in the open disclosure process.

- Related to this, making provision for support or representation in the disclosure process by an advocate where the person wants or needs this. In many cases, a person with intellectual disability will be able to fully participate in open disclosure if they receive the adjustments and advocacy support that they need. In some cases, the role of the advocate may need to be much more akin to that of a representative representing the will, preferences and rights of the person.

In this submission, we make recommendations for amendments to the draft framework to better address these key points.

Health inequalities for people with intellectual disability

There are approximately 500,000 people with intellectual disability in Australia.

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].

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

- 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]

Key open disclosure points for people with intellectual disability

The key open disclosure issues from our perspective are:

- Ensuring that people with intellectual disability receive adjustments and supports to maximise their opportunities to fully participate in the open disclosure process.

- Related to this, making provision for support or representation in the disclosure process by an advocate where the person wants or needs this. In many cases, a person with intellectual disability will be able to fully participate in open disclosure if they receive the adjustments and advocacy support that they need. In some cases, the role of the advocate may need to be much more akin to that of a representative representing the will, preferences and rights of the person.

These points arise similarly for people with dementia, acquired brain injuries and other cognitive and mental health impairments.

We emphasise the following interrelated matters:

1. Article 12 of the United Nations Convention on the Rights of Persons with Disabilities with its focus on people with disability having "legal capacity on an equal basis with others in all aspects of life" and "the support they may require in exercising their legal capacity."

2. The constantly growing emphasis in law and policy on supported decision making rather than paternalistic substitute decision making. This movement was reflected in the reports of the Aged Care and Disability Royal Commissions and in government aged care and disability policies. See: Supported decision making policy | NDIS; Supported decision-making under the new Aged Care Act | Australian Government Department of Health, Disability and Ageing; and Supported Decision Making Hub - Council for Intellectual Disability

3. The well-established role of advocacy for people with disabilities in Australia. In the context of government funded advocacy programs:

   > "A disability advocate can support you in a range of ways including: to help you understand what your rights are and how to assert them; to help you access services and support to improve your ability and confidence in all areas of life; by acting on your behalf to solve issues before they become a crisis or harm you further. An advocate is in your corner. They are your champion. They are there to support you and speak on your behalf when you don't feel confident to do so. They can also provide support and information so you feel more confident advocating for yourself." (Disability advocacy for individuals fact sheet, Department of Social Services.
   >
   > "Advocates support or work on behalf of a person with disability to help them to speak out and defend their rights and interests." An advocate must "be independent and be on the side of the person with disabilities and no-one else's."
   > What is Advocacy - Disability Advocacy Network Australia

4. Since open disclosure processes do not usually lead to any legally enforceable outcomes, an advocate would not usually need legal authority to represent a

patient. The advocate would usually be a family member, friend or professional disability advocate.

5. In limited cases, an advocate may have legal authority to represent a patient in an open disclosure process, via the provisions of guardianship or financial management/administration/attorney appointments by the person or a court or tribunal. However, those appointments by no means generally give such specific authority (as is pointed out in the existing Open Disclosure Framework, at section 4.4.4. (The advocate may be the same person as the "person responsible" who can give substitute consent to medical treatment under the Guardianship Act 1987 NSW or a "medical treatment decision maker" under the Medical Treatment Planning and Decisions Act 2016 Vic and similar legislation in other jurisdictions. However, at least in NSW and Victoria and we expect in other jurisdictions, the formal legal authority of a "person responsible" or "medical treatment decision maker" would not extend beyond consent to treatment to representation in open disclosure.)

6. Since people with disability will not usually have a "substitute decision maker" who has legal authority to represent them in an open disclosure process, it would be better for the framework to use the word "advocate" rather than "substitute decision maker".

We appreciate that the continuum through from providing a little support to a patient through to fully representing them can seem complex but we have attempted to capture this continuum in our suggestions.

Extracts from draft Framework with our suggested changes

Below we have listed specific points and line references in the draft Framework where we are suggesting amendments. Our suggested insertions are <u>underlined</u>.

- **Formal open disclosure (lines 110-116)**
  A formal open disclosure may occur after initial disclosure and is an organised process that is led by a senior clinical leader of the health service. The timing, place and pace of formal open disclosure should be responsive to the needs and expectations of the patient and their support people.

The open disclosure process may take some time to finalise and may not follow a step-by-step process. This will be based on the needs of the patient and/or their support people and may be different from patient to patient. For instance, a patient may not want to discuss their experience until time has elapsed, or sufficient trust has been built which may take several meetings. Once there is agreement to proceed and to help prepare and plan for a formal open disclosure.

Support the patient (129-140)

- Identify any specific needs of the patient and/or their support people to enable participation. The emphasis should be on identifying and addressing any barriers to the patient feeling able to directly participate. However, some people may still prefer to defer to family members, advocates, guardians, community leaders, or
- community elders in discussions. Some people may need interpreters, or a patient liaison officer to support participation.
- In situations where there is difficulty conducting open disclosure or finding an agreeable outcome, arrange for an independent facilitator to support ongoing discussions.
- Arrange the first formal meeting in consultation with the patient and their support people.
- Ask the patient and/or their support people if they would like to nominate a contact person. A nominated contact person is the agreed individual who is formally identified as the recipient 136 of information regarding the patient's care through any local legal process and associated requirements.
- Ensure nominated contacts are by default entitled to receive information and participate in open disclosure unless otherwise instructed by the patient.

Open disclosure should be a conversation where clinicians, the patient and their support people are able to share their experiences. The patient and their support people should be able to seek clarification and be provided with information and access to services such as social work, psychology and after-hours helplines as required. The patient and support people should be encouraged to talk about the effect the harm has had upon their life. It is important for the patient and their support people that their views and concerns are heard and understood (p221-223).

- **Advocacy and support (264-266)**
  People will often need additional help and support after experiencing an adverse event. Support may be provided by family members, support people, social workers, religious representatives or trained patient or disability advocates.

- **Communication and accessibility (332-336)**
  Clear, open and effective communication is one of the most important aspects of open disclosure (8). Some people may require a different style of communication to help them understand what has happened or is happening to them. It is the health service's responsibility to work with the patient and/or their support people to identify how best to meet the patient's communication needs. This might include access to language services, Auslan, Deaf relay, information in Easy Read or interpreters.

- **People with disability (384-401)**
  People with disability should be involved directly in the open disclosure process unless they do not want to ~~if they are able~~. The default starting point should be that the person is offered all adjustments and support that they need to fully participate in the process and make their own decisions.

  If the person does not attend, an advocate should attend for them, ~~and if not, their substitute decision maker should be invited to act on their behalf.~~

  Reasonable adjustments are essential components of safety and quality. Article 12 of the United Nations Conventions of the Rights of Persons with the Disability affords all people with disability equality under the law and the right to support they need to exercise their legal capacity (9). It is important to acknowledge if a lack of reasonable adjustments contributed to the adverse event.

  For people with disability there are several important actions to ensure inclusion in the open disclosure process. These actions are:
  - Identify a support person of the patient's choice unless the patient does not want a support person.
  - Identify and include an advocate ~~substitute decision maker~~ if the patient has or needs one.

- Adjust verbal and written communication so that the patient can understand the information to the best of their ability and use any available communication aids that have been designed for the patient.
- Include the patient with disability in all meetings and written communications (unless there is a reason why the patient cannot be part of the process)
- Allow extra time for the open disclosure processes, consider the disability support needs of the patient and their support people when making appointments. This may include the time of day, the space used, parking, regular breaks and waiting times.
- Take a trauma informed approach. A high proportion of people with disability have experienced trauma in their lives.

Glossary

- **Replace 'Substitute decision-maker' with 'Advocate'** (664-667) and amend the definition to read:
  "A person who is independent from the health service and who supports a patient to participate in open disclosure and where appropriate represents the patient's views and rights in the process. The advocate might be a family member, friend or professional advocate. In some cases, the advocate will have legal authority to represent the patient in the process. This will be so if the person, legislation or a court or tribunal has given them that authority. Parents generally have authority to represent their children. Relevant legislation varies around Australia."

- **Support person** (669-676) and amend the definition to read:
  "An individual who has a relationship with the consumer. References to 'support person' in this document can include:
  - family members/ next of kin
  - support people
  - friends, a partner or other person who cares for the consumer
  - guardians or substitute decision makers
  - social workers or religious representatives
  - where available, trained consumer or disability advocates."

Additionally, references to 'support person' should be read with the words, 'where appropriate' (676).

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Finally, but importantly, **we recommend that a change of title to the framework be considered**. “Open disclosure framework” does not have a clear meaning to lay readers and would be very obscure to people with intellectual disability.

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