National Centre of Excellence in Intellectual Disability Health

NATIONAL CENTRE OF EXCELLENCE IN INTELLECTUAL DISABILITY HEALTH

Consultation on draft 3rd Edition of National Safety and Quality Health Service Standards

These are the standards that all hospitals in Australia are required to comply with.

Key points

1. There are approximately 560,000 people with intellectual disability in Australia.

2. A very strong research base shows that people with intellectual disability experience extreme disadvantage in the Australian health care system. This includes twice the usual rate of potentially avoidable deaths, four times the rate of potentially preventable hospitalisations and dying 27 years earlier.

3. Most hospital clinicians have minimal undergraduate or continuing education in the needs of people with intellectual disability. They commonly show inadequate understanding of their needs and often show unconscious bias concerning their needs and quality of life.

4. Hospital clinicians do not routinely think about people with intellectual disability when faced with broader expressions like “equity”, “disability”, “cognitive disability” or “cognitive impairment”.

5. The Standards therefore need to include a specific focus on people with intellectual disability.

6. We welcome the inclusion of a section on “Equity” in the Introduction to the draft Standards. However, for that section to have impact, it requires at least a succinct subsection focused on each equity population, including specifically people with intellectual disability. The section on people with intellectual disability should

reflect paras 2-4 above and other key aspects of disadvantage experienced by people with intellectual disability in the health system.

7. The Standards should require hospitals to give ongoing and specific consideration to the needs of people with intellectual disability and each other equity population in implementing relevant Standards. This should include
    a. A requirement to focus on intersectional needs, for example needs of a First Nations person with intellectual disability.
    b. A requirement to identify and avoid disadvantage related to stigma.
    c. A need to act on relevant ACSQHC user guides, including the Standards User Guide for the Health Care of People with Intellectual Disability, and the Standards User guide for Aboriginal and Torres Strait Islander health.

8. We welcome draft Standard 1.10 c. which requires hospitals to have organisational systems to "provide equitable access to health care for people with a disability and identify and action the need for reasonable adjustments". However, this requirement is too general so that there will be tendency to focus on physical and sensory disability and not intellectual disability. The Standard should be reworded to read:

    Provide equitable access to health care for people with intellectual, physical, sensory and other disabilities and action the need for:
    - Reasonable adjustments
    - Steps to counter conscious and unconscious bias
    - Avoiding diagnostic overshadowing, specifically the assumption that symptoms relate to a person's disability rather than to a health condition.

9. "Reasonable adjustments" are fundamental to providing equitable care to people with disability but hospital personnel commonly have very limited understanding of them. An additional Standard should be created along the following lines:

Reasonable adjustments

Hospitals should ensure reasonable adjustments to meet the needs of people with disability by having systems to:

- Identify consumers with disabilities including their types of disability and intersectional needs.
- In conjunction with the person and their families, carers and disability support providers, identify reasonable adjustments the consumer needs in relation to matters including communication, time needed for interactions, support for decision making, comfortable environments, waiting times, behaviour support, and support and sedation for intrusive treatments.
- Provide identified reasonable adjustments.
- Train clinicians in identifying and providing reasonable adjustments.
- Monitor and audit to assess whether reasonable adjustments have been made.

10. The need to identify and act on reasonable adjustments should also be restated in draft Standards 2.04 and 2.05 (clinical assessments and plans of care).

11. The draft Standards do not but should include requirements for trauma informed care including in relation to trauma resulting from medical treatment.

12. Behaviours of concern (2.11 and 2.12) – There should be specific requirements in relation to:
    a. Use of positive behaviour support.
    b. The need to comply with legal requirements for consent or authorisation of restrictive practices.

13. Recognising and responding to acute deterioration (2.16-2.18) – A consumer's "usual baseline" should be documented on admission to avoid diagnostic overshadowing. All too often, deterioration is not adequately recognised because hospital staff assume a person's presentation relates to their disability.

14. Coordinated and connected care (2.19- 2.22) –
    a. There should be specific inclusion of any "disability support services" in the list of those to be involved in coordination of care. All too often, this does not occur to the detriment of a person with disability
    b. There should be a specific requirement for hospitals to liaise with disability support services and families to
        i. clarify the disability support needs of a consumer and whether these have significantly altered as a result of a health condition, and
        ii. resolve arrangements to meet those needs both in hospital and on discharge.

15. Safe environments – Standard 3.01 should be extended by:
    a. Amending the Purpose statement to encompass accessibility. The Purpose statement should read, "Care environments are safe, accessible, culturally welcoming and therapeutic.:
    b. Including requirements to:
        i. Provide hospital environments that will minimise anxiety and maximise psychological comfort for individuals.
        ii. Where appropriate, offer ambulatory and outreach models of care.

16. Health care record systems (3.04) – These should record any disability and related needs for reasonable adjustments. (The Single Digital Patient Record currently being piloted by NSW Health incorporates this feature.)

17. Medicines safety and quality (3.10-3.12)- There should be a requirement to comply with relevant authoritative guidelines such as the ACSQHC Psychotropic Medicines in Cognitive Disability or Impairment Clinical Care Standard.

18. The glossary should be amended to include definitions of the following expressions which will not routinely be understood in hospitals:
    a. Reasonable adjustments
    b. "Disability" and different kinds of disability including "intellectual disability"
    c. Positive behaviour support

d. Diagnostic overshadowing

19. "Substitute decision maker" is defined in the Glossary as a person authorised to make decisions for a person "who has lost decision-making capacity". This incorrectly indicates that capacity is an all or nothing concept. The words "who has lost decision-making capacity" should be replaced by "who lacks capacity to make a particular decision".

20. The definition of "bias" should be elaborated on to explain both conscious and unconscious bias.

21. Like the existing Standards, the new Standards should be accompanied by a Guide for Hospitals which has to be considered by hospitals implementing the Standards and by accreditation agencies. The existing intellectual disability User Guide is a valuable document but does not carry sufficient authority to be routinely considered by hospitals and assessors. Considerable material related to people with intellectual disability should be incorporated into the new Guide for Hospitals.

Fulfilling Government commitments in response to the DRC

We argue that action on our recommendations is required to meet the commitments of Australian Governments that the revised Standards will "ensure equal access to health care services for all people with disability throughout life".

DRC Recommendation 6.31(a) was to embed the right of people with disability to good health care in key policies and in legislation – the Australian Charter of Healthcare Rights, the National Quality and Safety Health Service Standards and Community Healthcare Standards

In the 2024 joint response of all Australian Governments, they said "Accept" to this recommendation and stated:

> Governments are committed to ensuring key policy instruments and plans support an inclusive Australian society that ensures people with disability have access to health care services that address their needs. The Australian Government, through

> the Australian Commission on Safety and Quality in Health Care and in consultation with Commonwealth and State and Territory health governments, will develop a plan to update key policy instruments to ensure they articulate the requirements for safe and equitable access to health services for people with disability.

In their 2025 update on action, the governments said:

> The ACSQHC will continue to undertake wide consultation with key stakeholder groups and the public when developing the third edition of the Standards and supporting resources to ensure equal access to health care services for all people with disability throughout life.