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

Sent via email: nsqhssthirdedition@safetyandquality.gov.au

30 September 2025

Dear Professor Duggan,

Letter of support for submission by the National Centre for Excellence in Intellectual Disability Health

I write on behalf of Inclusion Australia to express our strong support for the submission prepared by the National Centre for Excellence in Intellectual Disability Health (the Centre) to the consultation on the National Safety and Quality Health Service (NSQHS) Standards (third edition). We are grateful to the Commission for the opportunity to provide this letter.

As the national voice of people with an intellectual disability and their families, we welcome the Centre's contribution and wish to affirm the importance of its recommendations to ensure that the Standards contains a strong focus on people with an intellectual disability and meaningfully addresses the stark health inequalities they experience.

The Centre's recommendations reflect long-standing issues we regularly hear from our community through our member organisations across Australia. As the Centre's submission highlights, in Australia, approximately 550,000 people with an intellectual disability face significant health inequalities and multiple barriers to accessing health care that meets their needs. In comparison with the general population, people with intellectual disability experience, among other inequities:

- Premature mortality 27 years earlier.
- More than double the proportion of potentially avoidable deaths (38%).
- Four times the rate of potentially preventable hospitalisations, including up to eight times higher for acute conditions and three times higher for vaccine-preventable conditions.

- Twice the rate of hospitalisations and emergency presentations, with admissions on average twice as long and twice as expensive.[1]

People with an intellectual disability are also less likely to have their preventative health care needs met through primary care compared to the general population, contributing to high acute care service use. This gap is well recognised by the Department and in the National Roadmap for Improving the Health of People with Intellectual Disability. The Department recently funded Inclusion Australia to create resources to encourage more people with an intellectual disability to see their GP for their Annual Health Assessment through our It's Doctor Time! project.

The Disability Royal Commission described these inequities in the healthcare system as "systemic neglect" and called for urgent reform.[2] The Australian Government, in its response, has committed to ensuring that key policy instruments such as the NSQHS Standards clearly articulate requirements for safe and equitable care for people with disability. The third edition of the Standards is therefore a critical opportunity to drive meaningful change.

We strongly support the Centre's recommendations detailed on page 16-22 of their submission, which at a high level include that:

- The Standards establish a specific Diversity Standard, placed at the beginning of the framework to ensure it informs all subsequent Standards.
- The Diversity Standard explicitly identify people with an intellectual disability as a priority group, alongside others who face systemic disadvantage, with recognition of intersectional disadvantage.
- Within the Diversity Standard, the highest priority actions required to meet diverse needs in hospital are included, such as: treating all patients with respect and kindness; communicating in a way that makes sense to the individual (including providing accessible information); and recognising and responding to intersectionality.
- The Diversity Standard also set out specific actions required for each group. For people with an intellectual disability, required actions must include:

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[1] The NSW data linkage work of the Department of Developmental Disability Neuropsychiatry, UNSW (now incorporated into the National Centre), explores the health outcomes for people with intellectual disability. These linkage studies were based on approximately 1.1% of the NSW population who were identified as having intellectual disability. In the absence of any available source of population health data at a national level, NSW findings can be taken as nationally representative. Below is a summary of some of the findings.
Florio, T. and J. Trollor, Mortality among a Cohort of Persons with an Intellectual Disability in New South Wales, Australia. Journal of Applied Research in Intellectual Disabilities, 2015. 28(5): p. 383-393.; Trollor J, Srasuebkul P, Xu H, Howlett S. Cause of death and potentially avoidable deaths in Australian adults with intellectual disability using retrospective linked data. BMJ Open. 2017 Feb 7;7(2):e013489; Weise, J.C., Srasuebkul, P. and Trollor, J.N. Potentially preventable hospitalisations of people with intellectual disability in New South Wales. Med J Aust, 2021; 215: 31-36.; Trollor, J.; Reeve, R.; Srasuebkul, P. Utilisation and costs of hospital services for patients with intellectual disabilities. Journal of Intellectual Disability Research, 2016; 60: 753.

[2] Disability Royal Commission. 2023. Final Report, Volume 6. Retrieved from: https://disability.royalcommission.gov.au/system/files/2023-09/Final%20Report%20-%20Volume%206%2C%20Enabling%20autonomy%20and%20access.pdf

    - Identification of intellectual disability
    - Accessible communication (including Easy Read and use of Augmentative and Alternative Communication (AAC))
    - Provision of reasonable adjustments
    - Countering unconscious bias and diagnostic overshadowing
    - Supported decision-making
    - Trauma-informed practice
    - Non-discrimination in access to services.
- Other Standards regularly reference and integrate these actions, embedding equitable care for people with an intellectual disability across the framework.

Incorporating these changes will not only strengthen the Standards but also provide a clear foundation and important measures for safer, more inclusive and more effective health care for people with an intellectual disability and their families.

We encourage the Commission to continue to work closely with the Centre, people with intellectual disability, and Disability Representative Organisations to ensure the development of the third edition of the Standards addresses the systemic neglect experienced by people with an intellectual disability and delivers lasting impact to all Australians accessing the healthcare system.

We would also welcome the opportunity to discuss with you or your team any of the issues raised here further.

Warm regards,

Maeve Kennedy
Acting CEO
Inclusion Australia