National Centre of Excellence in Intellectual Disability Health

30th July 2025

Ms Angela Jackson &
Mr Selwyn Button
Commissioners for the National Mental Health and Suicide Prevention Review
Australian Government Productivity Commission
mentalhealthreview@pc.gov.au

Dear Commissioners,

Re: Submission in response to the National Mental Health and Suicide Prevention Agreement review's interim report

Thank you for the opportunity to provide feedback on the interim report of the National Mental Health and Suicide Prevention Agreement (herein, the Agreement) review.

The Agreement represents a shared commitment by the Commonwealth, state and territory governments to work together to improve the mental health and wellbeing of all Australians and to reduce the rate of suicide towards zero. The original Agreement identified several priority areas, including whole-of-government approaches to mental health and suicide prevention, a focus on safety and quality, the need for a skilled and sustainable workforce, and improved data collection to drive system accountability and improvement.

The interim review concludes that the current Agreement is 'not fit for purpose' - noting that outcomes have not improved and that its commitments have failed to translate into meaningful or measurable reform. The report calls for urgent action and the development of a new, fit-for-purpose Agreement that delivers tangible improvements in mental health outcomes.

We strongly support this direction and emphasise the urgent need for the new Agreement to explicitly recognise and address the mental health needs of people with intellectual disability - a population that is persistently underserved by national mental health policy and practice. For a new Agreement to be effective, its development must include genuine co-design with people with lived experience and commit to targeted investment in the delivery of accessible services, expansion of an appropriately trained specialist workforce, and robust data collection to drive continued systems

improvement. These elements will ensure people with intellectual disability are visible throughout the mental health system and receive care that is equitable and appropriately adjusted to meet their individual needs.

Background

Who we are

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 UNSW Sydney, Centre for Disability Studies (University of Sydney), Council for Intellectual Disability, Down Syndrome Australia, First Peoples Disability Network, Queensland Centre of Excellence in Intellectual Disability and Autism Health, Queenslanders with Disability Network, University of Melbourne and The Kids Research Institute. 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 living with intellectual disability in Australia receive the highest attainable level of healthcare.

Centre staff bring strong expertise in the mental health of people with intellectual disability, including Scientia Professor Julian Trollor and Associate Professor Rebecca Koncz who holds the UNSW Chair in Intellectual Disability Mental Health.

The systemic neglect experienced by people with intellectual disability in our healthcare system

In Australia, people with intellectual disability face stark health inequalities and multiple barriers to accessing health care that meets their needs. The experience of this group was pivotal to the finding by the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (DRC) of systemic neglect in health care for people with cognitive disability. Outcomes for people with intellectual disability are characterised by:

- Significant premature mortality, with the median age of death being 27 years earlier than the general population (Trollor et al., 2017).
- More than double the proportion of potentially avoidable deaths compared to the general population (Trollor et al., 2017).
- Four times the rate of potentially preventable hospitalisations (Weise et al., 2021).

Mental health disparities are stark, including:

- The near ubiquitous rates of mental health conditions in people with intellectual disability (76%), which is twice the rate experienced by the general population (38%), across a wide range of conditions (anxiety disorders, depression, psychotic illness, substance use disorders and personality disorders) (Arnold et al., 2025).
- Disproportionately high rates of suicide attempts and self-harm compared to the general population (6.7% vs 2.8%) (Arnold et al., 2025).
- Significantly higher rates of neurodevelopmental conditions, including autism and ADHD, highlighting the complexity and intersectional needs of this cohort (Arnold et al., 2025).
- Mental health costs being grossly inflated, with the 1.1% of people in NSW with intellectual disability accounting for 14% of inpatient mental health expenditure in a given financial year (Srasuebkul et al., 2021).

The interim report has identified systemic gaps that have ultimately rendered the Agreement 'not fit for purpose'. The mental health system lacks integration which results in service discontinuity and needs not been adequately addressed. Furthermore, priority populations - including people with disability, such as those with intellectual disability and autism - have not experienced improved outcomes under the current Agreement.

Recommendations

We strongly support the recommendation that a new National Agreement is essential to address enduring policy and service gaps, and to clearly delineate the respective roles and responsibilities of Commonwealth, state and territory governments in delivering mental health reform.

For the new Agreement to be effective, we agree it must be developed through a transparent, inclusive, and adequately resourced co-design process, with a realistic development timeframe. We also emphasise the importance of anchoring the Agreement in a clear theory of change - one that articulates actionable outcomes and includes mechanisms for robust monitoring, evaluation, and continuous quality improvement. Transparent governance and accountability structures must underpin this work.

To ensure that the mental health needs of people with intellectual disability are fully addressed, we recommend the following elements must be embedded in the next iteration of the Agreement:

1. People with intellectual disability must be explicitly recognised as a priority stakeholder group in the development of the new Agreement.
2. People with intellectual disability must be involved in meaningful co-design throughout its development, including representation of people with lived experience, families, carers, advocates, and specialist clinicians.
3. The new Agreement must commit to targeted investment in:
    a. Inclusive, co-designed mental health services. All mental health services must embed reasonable adjustments as core practice, and ensure supported decision-making is standard in all aspects of treatment planning and service delivery.
    b. Mainstream mental health services supported by specialists in intellectual disability mental health as a source of consultancy and training.
    c. Tailored early intervention mental health programs that are developmentally appropriate and responsive to the unique needs of people with intellectual disability.
    d. Specialised crisis response models, equipped to respond with trauma-informed approaches, sensitive to individual sensory and communication preferences and needs.
    e. Service integration, with mechanisms to bridge Commonwealth-funded (e.g. primary care) and state or territory funded (e.g. public mental health) services to avoid fragmentation and ensure continuity of care.
    f. Training, recruitment and accreditation of a skilled mental health workforce with capability in intellectual disability and autism. This should include establishing recognised pathways for specialist practice.
    g. Data collection which requires services to report on access, experience and outcomes for people with intellectual disability, and use service-level indicators to drive further quality improvement and policy development.

These inclusions are essential to ensuring that the mental health system responds to the needs of all Australians, including people with intellectual disability.

Thank you for the opportunity to participate and we look forward to seeing our feedback incorporated into the final report. We would also welcome the opportunity to participate in further consultation. Should you require any further information, please contact us

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Regards,

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