National Centre of Excellence in Intellectual Disability Health

Primary Health Networks and Partnerships Branch
Primary Care Division, Primary and Community Care Group
Australian Government Department of Health and Aged Care
PO Box 6022 House of Representatives
Parliament House
Canberra ACT 2600

Sent via email: phn@health.gov.au

21 January 2025

Dear Primary Health Networks and Partnerships Branch,

Review of Primary Health Network Business Model & Mental Health Flexible Funding Model

We write on behalf of the National Centre of Excellence in Intellectual Disability Health (NCEIDH) to provide input on the Review of Primary Health Network Business Model & Mental Health Flexible Funding Model. We are providing a written response separate to the online questionnaire, which we found inhibited our capacity to express our views.

The NCEIDH was established in 2023 with funding from the Australian Government to help improve the health of people with intellectual disability, in line with the National Roadmap for Improving the Health of People with Disability. Around 1.8 per cent of the population[1], or around 490,000 Australians in 2024[2], have an intellectual disability. People with intellectual disability experience significant health inequities compared to other Australians, including:

- median age at death of 54 years, some 27 years earlier than the general population[3],
- a very high proportion of potentially avoidable deaths (38%), more than double that of the general population[4],
- 1.6 times the rate of emergency department use, longer wait times and twice the rate of hospital admissions[5],
- higher rates of mental illness, including 3-4 times the prevalence of psychiatric disorders among young people[6],

- higher rates of obesity and other potentially modifiable risk factors for chronic disease[7],
- lower use of preventative healthcare services and significant barriers to care in general practice[1].

Our emerging understanding is that the health outcomes for people with intellectual disability are one of the most disadvantaged of any population group in Australia, but this remains inadequately recognised and addressed by PHNs. The 2023 Royal Commission into the Violence, Abuse, Neglect and Exploitation of People with Disability found, largely on evidence of those with intellectual disability or autism, that those living with cognitive disability experience systemic neglect. It found that a vision needs to be set to target this group in the PHN business model to allow PHNs to address preventive and chronic care needs for this group. Unless this vision is set, we risk missing a much-needed opportunity to address this situation.

PHN Program

The NCEIDH considers Primary Health Networks (PHNs) to be a vital part of the health system that have significant potential to improve health system experience and health system outcomes, as well as health and mental health outcomes, for people with intellectual disability. This applies across all three PHN roles: integrating the health system at local and regional level; commissioning primary care and mental health services to fill gaps in the system; and building the capacity of primary care services. These health system roles of PHNs are particularly important for population groups with complex needs, including people with intellectual disability, as these groups experience significant disadvantage, limited health literacy and limited capacity to navigate the health system without assistance.

However, PHNs have to date had limited capacity to direct attention or resources to improving health services and outcomes for people with intellectual disability.

- The Australian Government provided specific funding for the Primary Care Enhancement Program (PCEP) in 2024 to trial approaches to improving primary care for people with intellectual disability in four PHN regions, with a view to scaling up successful approaches across all PHNs. An evaluation of the PCEP in 2024 showed some success, albeit limited by the disruption of the COVID-19 pandemic,

and the Government has extended the program in the initial four PHNs to June 2026. The future of the program beyond 2026 however is not clear.

- It is currently up to PHNs whether to invest their core flexible funding in improving care for people with intellectual disability. However, PHNs are largely unaware of the health needs of this group a local population level because of lack of local and nationally reported data. Further, PHNs are constrained by the current, limited quantum of core flexible funding available to them, and the need to prioritise use of this funding in line with annual population health needs assessments processes. Given the quantum of funding and the nature of these processes, PHNs cannot comprehensively reach all populations in need, but they must target those most in need. As a result, despite significant health disadvantages, as a population group of only 1.8% people with intellectual disability have not generally been considered by individual PHNs as a priority group. The availability of specific funding to some PHNs under PCEP also weighs against others using their flexible funds for this population.

PHNs have significant potential to improve the health of people with intellectual disability, for example in the following areas:

1. Health Pathways. All PHNs could work with their corresponding local hospital networks to develop formal health pathways for people with intellectual disability. This would improve the confidence of GPs and others in the system in helping people with intellectual disability access specialised services and navigate referral pathways. To ensure a holistic, person-centred approach, PHNs should work to extend the pathways beyond hospital and specialist health services to include genetics and diagnostic services, mental health services, preventive health services, ambulatory care services, chronic and complex care, palliative care, disability services and social support services.

2. Primary care workforce capacity building. Some PHNs participating in PCEP have trialled approaches to building GP and primary care nursing staff confidence and capacity to meet the health and mental health needs of people with intellectual disability through training and continuing professional development opportunities. In general, these initiatives have been impactful. The tools and the learnings from these trials could be taken up across all PHNs, ideally with funding support for the

PHNs and for the participating primary care workforce – which could usefully be extended over time to practice management workers and allied health providers.

3. Support for improved take-up of MBS-funded annual health assessments for people with intellectual disability in general practice, and better continuity of care underpinned by MyMedicare registration for people with intellectual disability. PHNs could support both these approaches through their regular practice support programs and could do significantly more with targeted funding for this purpose.

4. Multidisciplinary care. General practices with access to nurses and allied health professionals can provide better wraparound supports for people with intellectual disability, including preventive health, chronic disease management, mental health and health system navigation functions. PHN programs supporting multidisciplinary care could usefully be expanded to better support people with intellectual disability as a population.

Mental Health Flexible Funding Model

Mental health disparities have been well-documented, with people with intellectual disability experiencing significantly higher rates of mental ill health than the general population. This includes:

- 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%) (Trollor et al., in preparation), across a wide range of conditions:
    - Anxiety disorders, depression, psychotic illness, substance use disorders and personality disorders.
- Significantly higher rates of neurodevelopmental conditions, including autism and ADHD, highlighting the complexity and intersectional needs of this cohort.
- 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[8]

While State and Territory Governments have significant responsibility for delivering specialised mental health programs for people with intellectual disability, as a population, people with intellectual disability should be able to receive core components of their mental health care in primary care settings. Currently, however, they have a range of mental health needs that are not being met in primary care, such

as basic mental health assessments and treatment initiation for high prevalence conditions (such as depression and anxiety), and which should be considered by PHNs as part of their needs assessment and commissioning functions. The PHN Mental Health Flexible Funding Pool Model guidance[9] directs PHNs to consider the needs of people with comorbid mental health and intellectual disability under a stepped care approach and to establish partnerships with other organisations to facilitate 'joined up' services including for people with intellectual disability.

The extent to which PHNs are considering intellectual disability in their mental health planning and commissioning, and whether this is translating to real services for people with intellectual disability on the ground, is not clear. The Central and Eastern Sydney Joint Regional Mental Health and Suicide Prevention Plan 2024-26 commits "regional planning partners to upholding and supporting the principles outlined in 'The Guide: Accessible Mental Health Services for People with an Intellectual Disability, A guide for Providers" developed by 3DN, but makes no further reference to intellectual disability.

In our view, we strongly believe that Primary Health Networks and the Mental Health Flexible Funding Model provide the opportunity to make continued and further improvement to support the health and mental health of people with intellectual disability in the Australian health system as a matter of priority, and urge the Primary Health Networks and Partnerships Branch to take our comments into consideration in this review.

We thank you for the opportunity to provide feedback and would welcome the opportunity to discuss our comments further. Should you require any further information, please contact me at +61 2 8358 5923 or at sophie@cid.org.au.

Sincerely;

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