Delivering quality care more efficiently inquiry

Questionnaire response 80

Name: National Centre of Excellence in Intellectual Disability Health

Submission date: 13/06/2025

Participant background

1. For the purposes of this consultation, which of the following best describes you:

   I am an industry or advocacy organisation, professional association or peak body

2. Which of the following care sectors will your feedback relate to? Please select all that apply.

   Disability; Health

3. What kind of care supports, services and programs do you have experience with, and in what jurisdictions?

   The participant did not respond to this question.

1. Reform of quality and safety regulation to support a more cohesive care economy

1. To what extent do differences in quality and safety regulation make it costly or complex to provide or access care services?

   To a great extent

2. What are the reasons for your answer?

   The major issues of inconsistency of quality and safety regulation and quasi-regulation (through funding or service rules) that people with intellectual disability seeking quality care, their clinicians and supporters, consistently raise include:

   - transitions from paediatric care – largely managed by State and Territory-funded public hospital services, with paediatricians directing and coordinating care – to adult care, where people with intellectual disability need to find GPs willing to manage their care, with potential private costs if the GP does not bulk bill. Adults with intellectual disability needing specialist care may face delays or difficulties depending on the capacity of their GP to help them access and navigate public hospital services, and/or out-of-pocket costs if accessing private specialist care. Access to, and funding of, allied health care relies on complex and uncertain arrangements across the NDIS and health system, with rules for NDIS funding uncertain and changeable, access to publicly funded allied health in the community health and public hospital systems patchy, and significant out of pocket costs in the private system for allied health care. The advocacy body Development Disability Western Australia recently highlighted some of the risks at this transition point – see https://ddwa.org.au/mothers-struggle-with-wa-health-transition-gaps-for-her-son/
   - access to usual NDIS communication and behaviour supports while in hospital. Lack of access to these supports can create clinically dangerous issues for people with intellectual disability, who are at their most vulnerable when sick, may not understand clinical directions or be able to tolerate clinical interventions, and have difficulty communicating their needs. While hospitals ought to provide reasonable adjustments (eg calm environments, more time spent communicating simply, materials in easy read), this is unlikely to be fully effective in many situations. The NDIA is reviewing the rules in relation to this. The current situation appears to be that the general rule applied is that

people with disability cannot access their usual NDIS supports while in hospital and need to apply to the NDIA for an exception to this at the time they go to hospital. This is likely to lead to delays in appropriate care with associated clinical risks. Microboards Australia has methodically set out some of the causes and risks of hospitalisation for people with high support needs in a 2020 paper 'Delivering Better Health Outcomes for People with High Support Needs and/or Challenging Behaviour and their Families and Carers: Project Outcomes and An Exploration of the Literature' – see https://microboards.org.au/wp-content/uploads/2023/03/Delivering-Better-Health-Outcomes-Microboards-Australia-Report-2020.pdf
• inconsistencies in funding rules for palliative care. State and territory clinicians report gaps and conflicts between NDIS and State health funding rules in relation to end of life care, particularly for people in group homes. Issues of access to palliative care services for people with intellectual disability have been systematically reviewed by the University of New South Wales in the development of a tailored model of palliative care and toolkits for health professionals, people with intellectual disability and supporters available at https://nceidh.org.au/our-work/projects/improving-palliative-care-services-people-intellectual-disability.
• capacity of disability support workers to support people with disability in preventive health interventions, accessing appropriate health services when required and navigating the health system. The NDIS Quality and Safeguards Commission has developed capabilities in this area, but they are not matched with appropriate training for disability support workers. This can lead to poor preventive health behaviours in day-to-day life, delays in accessing care, and expensive and inappropriate avenues for care (calling an ambulance or attending an emergency department when a telehealth consultation or visit to a GP may be more appropriate). A 2024 study sets out some of the issues for disability support workers in effectively supporting the health of people with intellectual disability – see https://pmc.ncbi.nlm.nih.gov/articles/PMC10763292/

3. To what extent should quality and safety regulations be more aligned across the different care service sectors and jurisdictions?

To a great extent

4. What are the reasons for your answer?

There is an opportunity to foster dialogue between the NDIS and the health sector concerning quality and safety regulation, through a unified matrix that clearly defines the responsibilities of each industry and outlines how they can collaborate effectively.
As an example, the National Safety and Quality Service Standards User Guide for the Health Care of People with Intellectual Disability (the User Guide) has been developed in response to the significant poor health outcomes that people with intellectual disability experience. The User Guide provides specific standards and guides based on the recommendations of the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (DRC) Final Report.
There is great opportunity to align the User Guide with recommendations also in the National Roadmap for Improving the Health of People with Intellectual Disability (the Roadmap) https://www.health.gov.au/resources/publications/national-roadmap-for-improving-the-health-of-people-with-intellectual-disability?language=en
The Roadmap has key actions for better coordination with other sectors under section B4: Better coordination with other sectors and C: Better support for health care professionals to provide better care for people with intellectual disability. Under the Roadmap, the NDIS Quality and Safeguards Commission is tasked to:
- Review and update NDIS Practice Standards and Quality Indicators where appropriate,

to support healthy lifestyles and optimal access to health services for people with intellectual disability;

- Include in its Workforce Capability Framework, a strong focus on the role of disability workforce in supporting healthy lifestyles and access to health services.

This alignment would provide for better and more integrated care across the sectors to meet the needs of people with intellectual disability and is how quality and safety regulations need to be envisaged.

2. Embed collaborative commissioning to increase the integration of care services

1. What is your experience with collaborative commissioning

The Centre is not a commissioning organisation. However, we are a consortium of nine organisations united by the goal of working collaboratively to improve the health of people with intellectual disability. We believe that working collaboratively can improve the strength and capacity to achieve mutual goals; harnessing collective effort to avoid duplication.

The Centre made a submission to the 2025 Review of Primary Health Networks Business Model, which is available at https://nceidh.org.au/sites/default/files/2025-02/Submission-Review-Primary-Health-Network-Business-Model-Mental-Health-FFM.pdf.

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2. What are the benefits of pursuing greater collaborative commissioning?

For people with intellectual disability, collaborative commissioning may support better integrated care models, including in preventive health care, improved transition from hospital to home and avoidance of residential aged care placement.

Primary Health Networks (PHNs) are vital parts of the health system that have significant potential to improve health system experience and outcomes, and health outcomes, for people with intellectual disability. PHNs could work effectively with Local Health Networks (LHNs) and Aboriginal Community Controlled Health Organisations (ACCHOs) to support more effective and efficient health access and health pathways for people with intellectual disability. However, they need to be specifically funded and directed to do so.

People with intellectual disability are among the most disadvantaged in health, with overrepresentation in many health outcomes, despite only representing 1.8% of the population. To date, people with intellectual disability have not received much attention from PHNs through their population health needs assessments, other than those PHNs funded specifically under the Primary Care Enhancement Program (PCEP) – see https://www.health.gov.au/our-work/primary-care-enhancement-program-for-people-with-intellectual-disability. While the Government has extended the PCEP in the initial four PHNs to June 2026, the future of PCEP beyond 2026 is not clear.

The PHNs in PCEP have trialled approaches to building general practice and primary care nursing staff confidence and capacity to meet the health needs of people with intellectual disability through training and continuing professional development opportunities. In general, these initiatives have been impactful. The tools and learnings from these trials could be taken up across all PHNs, ideally with funding support for the PHNs and the participating primary care workforce. This could be usefully extended over time to practice management workers and allied health providers.

General practices with access to nurses and allied health professionals can also 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.

Local Hospital Networks (LHNs) are not generally well equipped to consider or cater to the needs of people with intellectual disability specifically and therefore need to engage with PHNs in collaborative commissioning in this area. Only NSW has specialised intellectual disability health teams at the LHN level and only NSW, Queensland, Victoria and SA have state-wide specialist teams in physical and/or mental health support for people with intellectual disability.

Through collaborative commissioning, 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 services, chronic and complex care, palliative care, disability services and social support services. Pathways need to be considered specifically for paediatric care, at the transition from paediatric care, throughout adult life and for palliative care. These are some examples of the benefits we see in pursuing greater collaborative commissioning.

3. What are the barriers to collaborative commissioning, and do you have any suggestions for solutions that would lead to better collaboration in the commissioning of care services?

Primarily, the current infrastructure for commissioning for PHNs, where they are allocated a relatively small amount of flexible funding to prioritise across all local population health needs, is a barrier preventing collaborative commissioning for smaller population groups. Specific funding and directives for collaborative commissioning targeted at improving the health outcomes of smaller disadvantaged population groups, such as people with intellectual disability, are much needed.

3. A national framework to support government investment in prevention

1. What are the main barriers to governments investing in evidence-based prevention programs across the care economy?

Proactive care in general practice is needed to improve the health of people with intellectual disability. The lack of sufficient specific funding for such care remains one of the main barriers to implementing evidenced-based prevention programs in the primary care field in relation to meeting the needs of people with intellectual disability. Financing for team-based multidisciplinary care and incentives for continuity of care in general practice are unclear and insufficient. For any new programs, evaluation measures need to be built in at the point of implementation.

A holistic approach to implementation of evidence-based programs is currently lacking and can lead to scope creep and unintended policy and program consequences that can be difficult to rectify without these being built into program design. For example, despite promising indications in the Primary Health Care 10 Year Plan 2022 - 2032, governments have not to date funded targeted programs for disadvantaged population groups in general practice (other than First Nations and residential aged care populations) or provided effective support for longer consultations under the Medicare Benefit Schedule (MBS). The focus has instead been on increasing bulk billing rates. While the plan considers an additional service incentive payment and practice incentives to support quality bundles of care and improved outcomes for people with intellectual disability in the medium term, the Government has not yet consulted on or announced a specific proposal.

Existing funding streams under the MBS are not being taken up. Only 7% of people with intellectual disability receive an annual health assessment, which attracts a relatively generous MBS rebate.

In addition, effective support for longer consultations under the MBS has not been provided. Longer consultations are needed to support reasonable adjustments in communications with people with intellectual disability.

2. What are some examples of successful prevention programs (this could include discontinued programs)?

MyMedicare provides a potential mechanism whereby blended or bundled funding models could be adopted to support preventive care in general practice for people with intellectual disability. The intellectual disability health Medical Research Future Fund (MRFF) funding stream could be used to trial such models.

Work being developed under the National Health and Medical Research Council (NHMRC) Partnership grant funding titled, “Improving preventive healthcare project” being conducted by the Partnership Team at the National Centre of Excellence in Intellectual Disability Health could provide evidence-based support for such an approach in general practice https://nceidh.org.au/our-work/projects/improving-preventive-healthcare.

This project commenced in February 2022 and will run for five years to 2027, consists of partners across jurisdictions and aims to:

1. Map how preventative health care needs of people with intellectual disability are represented in Commonwealth, State/Territory, and international policies.
2. Determine the reach and accessibility of preventive health strategies for people with intellectual disability.
3. Determine the impact current participation in preventative health strategies has on health service usage and health outcomes for people with intellectual disability.
4. Determine the feasibility of implementing change to enable people with intellectual disability to access and participate in preventative health care.

The continued investment and research in prevention is vital to improving the health outcomes of people with intellectual disability. The overrepresentation of people with intellectual disability using health services with poor outcomes, despite only representing 1.8% of the population, provides a backdrop to the importance of working upstream. The benefits of this include potentially reducing the burden on health care services and system spending, improving the quality of life of people with intellectual disability, which could extend to their families and carers, and better longevity of life.

3. How can governments better support investment in prevention activities that have broad and long-term benefits for the Australian community?

Current preventive strategies are broad-based and are not reaching disadvantaged populations who need them most, for example, people with intellectual disability.

More systematic approaches are needed to: (i) trial and evaluate targeted initiatives such as PCEP and preventive health/continuity of care in general practice for people with intellectual disability, (ii) routinely include health economic modelling and analysis in evaluations (iii) define pathways for program development, and (iv) upscale the implementation of initiatives that work.

An enhanced approach to continuing preventive health reform and implementation, which brings researchers together with consumers, advocates, the professions and government policy-makers, would serve government and each of these sectors well and assist in sustaining long-term benefits. Better integration across Commonwealth and State/Territory investment would similarly be beneficial, along with research funding more closely linked to preventive health policy development and implementation.

We appreciate the opportunity to comment on the Productivity Commission's Delivering quality care more efficiently inquiry. We would welcome the opportunity to engage further on these comments with the view to ensuring that the Australian health care system supports and upholds improved health outcomes for people with intellectual disability.