



Australian Government

Department of Health

Roundtable on the Health of People with Intellectual Disability

Friday, 2 August 2019

Summary and Recommendations

At the request of the Minister for Health, the Hon Greg Hunt MP, the Department convened a Roundtable on the Health of People with Intellectual Disability on 2 August 2019. The Roundtable was chaired by Simon Cotterell, First Assistant Secretary, Primary Care Division.

Attendance

The Roundtable was attended by key stakeholder groups including people with intellectual disability and carers, academic experts and health care providers across a range of disciplines. A full list of attendees is at [Appendix A](#).

Minister Hunt gave a pre-recorded video address. Minister Hunt:

- acknowledged the health inequities experienced by people with intellectual disability;
- undertook to raise with the Deans of the Medical Schools, the need for better training for medical professionals to help meet the needs of people with intellectual disability; and
- tasked the Roundtable with starting to develop a National Roadmap to improve health services for people with intellectual disability.

Presentations

A series of presentations was given to the Roundtable by consumer and carer participants, clinical and academic experts, the Council for Intellectual Disability (CID)/Inclusion Australia (IA), and PHNs, as summarised below.

Ms Shu Hua Chan, Chairperson, Council for Intellectual Disability

Ms Hua Chan gave her perspectives, as a person with intellectual disability, on the challenges that she has experienced in her interactions with the health system. She emphasised the need for equity in health for people with intellectual disability, and the need for doctors to receive more training in caring for people with intellectual disability. Ms Hua Chan noted that doctors often make assumptions about her health concerns and attribute them to her disability, rather than investigating her health symptoms further.

Ms Hua Chan spoke about the importance of skilled interpreters in aiding communication with health practitioners for people with intellectual disability from culturally and linguistically diverse backgrounds. Ms Hua Chan also advised that doctors need to be better skilled in explaining health problems, test results and medications in ways that can be easily understood by people with intellectual disability. She expressed the importance of doctors using simple language and taking more time to carefully explain test results or procedures to patients.

Dr Rebecca Kelly, Parent of a child with intellectual disability

Dr Kelly spoke about her experiences with the health system, as a parent of a child with an intellectual disability. Dr Kelly noted that she and her son, Ryan, have had both positive and negative experiences, with the positive experiences occurring when there has been continuity of care, and when the practitioner respects her knowledge about Ryan's health issues and needs.

Dr Kelly related some examples of negative experiences that she and Ryan have had with the health system, including practitioners having low expectations about the quality of his life and making assumptions that he is a burden to his family, and a number of occasions when practitioners failed to identify that procedures were causing Ryan pain. In those situations, doctors did not pick up on the different ways in which Ryan communicated or expressed feelings of pain.

Dr Kelly spoke about the traumatising impact of these events for Ryan. She emphasised that measures such as limiting unnecessary tests or procedures, and pre-medicating, are critical in minimising trauma for people with intellectual disability. Dr Kelly also emphasised that health professionals need to listen to parents about how to interact with children with intellectual disability, and trust that parents know and understand their children best.

Professor Julian Trollor, Chair, Intellectual Disability Mental Health, University of New South Wales

Professor Trollor outlined the research evidence on the significant health inequities experienced by people with intellectual disability, including that:

- as a group, people with intellectual disability experience multiple barriers to effective healthcare;
- for most people with intellectual disability, health status is unrelated to the cause of the disability;
- key determinants of health outcomes in the population relate to social and economic disadvantage, and lack of access to health services and skilled professionals;
- on average, people with intellectual disability have about 2.5 times the number of health conditions as people who do not have intellectual disability;
- approximately 50% of the health conditions of people with intellectual disability are undiagnosed;
- complexity and competing priorities result in many diagnosed conditions being inadequately managed by clinicians;
- preventative healthcare needs are poorly addressed;
- many people with intellectual disability experience mental health concerns, yet psychotropic prescribing rates far exceed the known prevalence of mental health disorders;
- prescribing is often poorly targeted, out of step with best practice and may expose the person to cardio-metabolic risks;
- compared to the general population, people with intellectual disability experience very high rates of Emergency Department (ED) presentation and inpatient stays, and when admitted people with intellectual disability stay approximately twice as long, resulting in very high health care costs for this group; and
- people with intellectual disability have very high rates of premature and potentially avoidable deaths.

Jim Simpson, Senior Advocate, Council for Intellectual Disability

Mr Simpson outlined the [Our Health Counts campaign](#) of CID and IA, and the joint proposal that they submitted to Minister Hunt and to the Department prior to the 2019 Federal Budget.

Mr Simpson noted that in light of Minister Hunt's video message to the Roundtable, CID is seeking consensus on elements of a National Roadmap to improve health services for people with intellectual disability. It was recommended that immediate action be taken on the proposed Primary Care Enhancement Program to be delivered through PHNs; and curriculum enhancement in medical and nursing schools.

Mr Simpson gave an overview of the key elements of the proposed Primary Care Enhancement Program, including:

- initial implementation in four PHNs (with a view to national rollout), to support and enhance the skills of GPs and other primary health care practitioners in providing health care to people with intellectual disability;
- training and support for the PHN lead sites from specialist intellectual disability health centres and local consumer organisations;
- the development of national resources including a training module for PHN staff, NDIS linkage tools, resources for GPs, and health promotion information for people with intellectual disability and their families; and
- evaluation of the effectiveness of the initial rollout of the program in the PHN lead sites.

Professor Nick Lennox, Director, Queensland Centre for Intellectual and Developmental Disability.

Professor Lennox spoke about the challenges in providing primary health care services for people with intellectual disability. In particular, these include non-identification of people with intellectual disability; practitioners being untrained and inexperienced in caring for people with intellectual disability; high levels of unrecognised health needs in this population; the tendency for practitioners to have a disease focus rather than a life consequences focus; the competing demands, time constraints and economic disincentives for practitioners; poor access to specialists; and inadequate health promotion and prevention activities for people with intellectual disability.

Professor Lennox highlighted the particular importance of continuity of care for this population, and that while GPs are good health system navigators, they need more support in this function. It was suggested that more support from practice nurses and nurse practitioners will be key in improving health system navigation, especially for people with highly complex needs. Professor Lennox also noted that the shortage of services for adults with intellectual disability means that paediatric services have difficulty in integrating with and referring patients to appropriate services for adults.

Professor Lennox emphasised the need for better education and support for GPs, better use of annual health assessments for people with intellectual disability under the MBS, and the development of better pathways to specialist care. He noted the synergies between the proposed Primary Care Enhancement Program, the role and objectives of PHNs, and primary health care workforce needs.

Dr Jacqueline Small, President, Australian Association of Developmental Disability Medicine

Dr Small spoke about the challenges faced by the health system in delivering integrated care, and its critical importance for people from vulnerable populations, including people with intellectual disability. Dr Small emphasised that as health systems are re-designed, there needs to be a focus on care that is genuinely patient-centred and outcomes focused; that supports coordination across different providers and settings; and promotes new and multidisciplinary models of care.

Dr Small gave an overview of key features required in re-imagining integrated models of care for people with intellectual disability, including specialised intellectual disability health teams (like those which have been established in NSW); mainstream health system capacity building among primary care physicians and specialist treating teams, and better models of care; health pathways that support integrated and coordinated care across the system; and seamless care which optimises patient experience.

Dr Small noted that achieving this will require a new funding model that reflects the way that integrated care needs to be arranged, and the level of work that it requires of clinicians.

Dr Small noted that access to care is a key challenge for vulnerable cohorts who struggle to navigate the health system; particularly NDIS participants, who have trouble finding and linking in to appropriate services. It was noted that these barriers create further trauma for children and their parents. Dr Small emphasised the need for a review of the NDIS to make the system accessible for users to navigate, and to increase its focus on optimising health outcomes.

PHN representatives

PHN representatives spoke about their organisations' current activities to improve the health of vulnerable populations, including people with disabilities. The PHNs indicated support for the proposed Primary Care Enhancement Program, and outlined ways in which their current initiatives, particularly practice support, HealthPathways, and other system improvement activities, could be leveraged to support implementation of the program.

Dr Brendan Goodger from Central and Eastern Sydney PHN (CESPHN) suggested that his organisation could work with the NDIA as a partner, better utilise data to understand service patterns of people with intellectual disability and find optimal points for effective intervention. Dr Goodger also noted the possibility of CESPHN working to tailor quality improvement initiatives for this cohort at the practice level, examine potential improvements to practice management software, enhance partnerships with primary care providers, and develop tailored resources to better support primary care.

Ms Samantha Sharp from Western Victoria PHN noted that it will be important to co-design the Primary Care Enhancement Program with consumers and their families, and that communities of practice can also be key in supporting quality improvement and system integration. Ms Sharp advised that Western Victoria PHN is planning to develop a community of practice for primary care clinicians, which would be run through a virtual collaborative platform. This will enable practitioners across different locations to share their experience, case studies, and their knowledge of the latest developments in supporting people with disability, including intellectual disability.

Ms Libby Dunstan advised that practitioners and communities in the Brisbane North PHN region have identified the same key issues regarding health services for people with intellectual disability, as mentioned by the other presenters. It was noted that there is an opportunity for PHNs to help establish a better interface between the health and disability systems. Ms Dunstan also emphasised the challenge in addressing the needs of all vulnerable patient groups, and working with practices where they have a range of patients with complex needs.

Mr John Gregg, CEO of Northern Queensland PHN, also highlighted the need to consider the particular challenges in providing access to quality, multi-disciplinary care for vulnerable populations, including people with intellectual disability, in rural and remote areas. He emphasised the need to develop innovative solutions (for example, use of digital health technology and virtual networks) to help address these challenges across all vulnerable population groups.

Roundtable discussion of the proposed Primary Health Enhancement Program

Attendees supported the implementation of the proposed Primary Care Enhancement Program, and discussed how best to take it forward.

The PHN representatives advocated for it to be funded and implemented in a sustainable way, rather than as a pilot, building on and tailoring PHNs' existing activities and capabilities in addressing the health needs of other vulnerable populations.

It was agreed that:

- the program would be developed in four PHN lead sites over four years, building on existing infrastructure and focusing on the needs of people with intellectual disability, with a view to national rollout across all PHN regions;
- the Department would have a separate discussion with PHNs regarding the selection process for the PHN lead sites;
- the Department would work with relevant PHNs, CID/IA, and other interested stakeholders, to further define the scope and detail of the program; and
- the model for the program would be inclusive, and consider the needs of people with a clinical diagnosis, as well as those with undiagnosed intellectual disability; consider the particular needs of Aboriginal and Torres Strait Islander people with intellectual disability; and incorporate innovation as a key feature.

Roundtable discussion of key elements to include in the National Roadmap

Participants discussed their suggestions for key elements to include in the National Roadmap for improving health services for people with intellectual disability, in the context of the health system as a whole.

In particular, attendees requested that in addition to the Primary Care Enhancement Program, the Roadmap include key elements on continuity of care; care coordination and integration within the health system; models of care for children and adults with intellectual disability; a focus on the transition from adolescence into adulthood; promoting and supporting greater use of MBS items for people with intellectual disability; alignment with the NDIS; coordination with other sectors; provider education and training; support for carers; and research, data and measurement.

It was agreed that the Department would circulate a draft outline of the National Roadmap as a key outcome from the Roundtable (see [Appendix B](#)).

Participants recommended that as the National Roadmap developed, consultations would also be required with other key stakeholders including state and territory governments, the Australian Commission on Safety and Quality in Health Care, the National Mental Health Commission, the Committee of the Presidents of Medical Colleges, and the dental and pharmacy sectors.

Recommendations from the Roundtable

The Roundtable recommended a number of key actions to improve the health of people with intellectual disability:

- 1) As proposed by Minister Hunt, working with the Deans of Medical Schools on curriculum development to improve the education of doctors to better meet the health needs of people with intellectual disability.
- 2) Similarly working with the Deans of Nursing Schools in relation to the education of nurses.
- 3) Implementing the Primary Care Enhancement Program proposed by CID, to be developed through four lead PHNs over four years, with a view to national rollout across all PHNs.
- 4) As proposed by Minister Hunt, developing a National Roadmap for improving health services for people with intellectual disability, including better health system integration, coordination and continuity of care and better coordination with the NDIS.
- 5) Establishing a network of centres of excellence on the health of people with intellectual disability, with at least one in each jurisdiction, building on existing centres.
- 6) Promoting better uptake of the existing MBS health assessment items for people with intellectual disability.
- 7) Paying priority attention to the issues of transition from paediatric to adult care for people with intellectual disability, with better models of care and coordination to be developed for all life stages.
- 8) Developing a national data asset on the health of people with intellectual disability.
- 9) Considering the needs of people with intellectual disability and their families in the development of all health policies and initiatives.

Next steps

It was agreed that:

- the Department would circulate the summary of the Roundtable discussions and recommendations, and the draft outline of the National Roadmap, to participants;
- the Department would provide Minister Hunt with a report on the outcomes and recommendations from the Roundtable, and the draft outline of the National Roadmap;
- the Department would write to the Committee of the Presidents of Medical Colleges about the outcomes of the Roundtable, and the development of the National Roadmap;
- the Department would recommend Minister Hunt write to the Deans of the Medical Schools about curriculum development in the care of people with intellectual disability;
- the Roundtable would re-convene in February 2020 to further discuss the development of the National Roadmap;
- consideration would be given to involving other stakeholders such as state and territory health agencies, the Deans of Medical Schools, the Committee of the allied health peak bodies, and the pharmacy sector as the Roadmap developed.

Appendices

[A: List of attendees](#)

[B: Outline of National Roadmap for Improving Health Services for People with Intellectual Disability](#)

Appendix A — List of attendees

Table 1 List of Attendees for Roundtable on the Health of People with Intellectual Disability, 2 August 2019

Name	Organisation
Ms Justine O'Neill, CEO	Council for Intellectual Disability
Mr Jim Simpson, Senior Advocate	Council for Intellectual Disability
Ms Shu Hua Chan, Chair	Council for Intellectual Disability
Mr David Briggs, Advocacy and Policy Officer Council for Intellectual Disability	Council for Intellectual Disability
Dr Rebecca Kelly, mother of a person with intellectual disability	Also Chair of Down Syndrome Tasmania
Professor Julian Trollor Head, Department of Developmental Disability Neuropsychiatry; and Chair of Intellectual Disability Mental Health	University of New South Wales
Professor Nick Lennox Former Director, Queensland Centre for Intellectual and Developmental Disability	University of Queensland
Dr Jacqueline Small President	Australian Association of Developmental Disability Medicine
Dr Jane Tracy Director, Centre for Disability Health Victoria	Centre for Disability Health Victoria
Dr James Best General Practitioner	Royal Australian College of General Practitioners
Dr Danielle McMullen GP Registrar	Australian Medical Association
Associate Professor John Allan, President	Royal Australasian College of Psychiatrists
Dr Chad Bennett, Psychiatrist	Royal Australian and New Zealand College of Psychiatrists
Associate Professor David Harley Director and Research Director of the Queensland Centre for Intellectual and Developmental Disability (QCIDD)	Royal Australasian College of Physicians
Ms Maree MacDermid, mother of a person with intellectual disability	Parent
Dr Cheryl McIntyre General Practitioner/Obstetrician, Senior Lecturer (General Practice) in the School of Rural Medicine	Affiliated with the Australian College of Rural and Remote Medicine
Dr Linda Mann	General Practitioner
Dr Linda Goddard	Charles Sturt University

Name	Organisation
Adjunct Senior Lecturer, School of Nursing and Midwifery	
Dr Ellen Skladzien, CEO	Down Syndrome Australia
Ms Leanne Wells, CEO	Consumers Health Forum
Dr Brendan Goodger, General Manager, Primary Care Improvement	Central and Eastern Sydney PHN
Ms Libby Dunstan, Deputy CEO	Brisbane North PHN
Ms Samantha Sharp, Director of Commissioning and Performance	Western Victoria PHN
Mr John Gregg, CEO	Northern Queensland PHN
Dr Gerry Naughtin, Strategic Adviser (Mental Health)	National Disability Insurance Agency
Simon Cotterell, First Assistant Secretary, Primary Care Division (Chaired the roundtable)	Department of Health
Mr Martin Rocks, Assistant Secretary, PHN Strategy Branch	Department of Health
Dr Bernie Towler, Medical Officer	Department of Health

Appendix B — Outline of National Roadmap for Improving Health Services for People with Intellectual Disability

Preface

Defining intellectual disability

It is proposed that the National Roadmap be underpinned by an approach that is inclusive of people who are suspected to have intellectual disability, but who have not had a formal assessment. This is based on evidence which shows that a significant proportion of people with intellectual disability have not had a formal assessment of their disability, and that this has additional negative implications for their health.

National Roadmap to become an element of the Primary Health Care 10 Year Plan

As noted at the Roundtable on the health of people with intellectual disability on 2 August 2019, the Roadmap will be an element of the Primary Health Care 10 Year Plan, which is currently being developed.

Consultations in developing and implementing the National Roadmap

At the Roundtable, it was agreed that the Department would work with the intellectual disability community and other stakeholders, in the development and implementation of the National Roadmap. Each component in the draft outline is identified for implementation within the short term (1-2 years), medium term (3-5 years), or long term (6-10 years).

Key elements of the National Roadmap

A. Better models of care for people with intellectual disability and their families

1. Models of care (SHORT TERM)

Better models of care need to be developed for children, youth, and adults with intellectual disability. This will better equip the health system to meet the needs of people with intellectual disability across their lifespan, and help to support access to services that are appropriate at each stage. In particular, there needs to be a greater focus on models of care to support young people with intellectual disability through the transition to adulthood.

2. Better use of existing MBS items (SHORT TERM)

Promoting, supporting and monitoring greater uptake and use of annual health assessment and other existing MBS items will be critical in improving preventative health care and health outcomes for people with intellectual disability.

3. Continuity of care (MEDIUM TERM)

Continuity of care is critically important in improving the health outcomes of people with intellectual disabilities. Suggested strategies include:

- a preventive health focus;
- increasing the focus on the needs of young people with intellectual disability, particularly during the transition to adulthood;
- voluntary patient enrolment, including assessment of all needs of the individual;
- software enhancements for GPs and specialists, and greater use of telehealth and case conferencing to support continuity of care and team-based care; and
- strategies to help ensure that doctors listen to people with intellectual disability and their families, and take the time to fully discuss health issues and treatment options.

4. Better care coordination and integration within the health system (MEDIUM TERM)

A number of key issues will need to be addressed in order to enable effective care coordination and integration within the health system for people with intellectual disability. These include:

- improving GP access to specialists in the health of people with intellectual disability for clinical advice and more comprehensive care;
- better integrating primary, specialist and hospital care, and increasing staff within hospitals who are trained and skilled in working with people with intellectual disability;
- better meeting the mental health needs of people with intellectual disability; and
- accessible case conferencing and better access to telehealth to support more coordinated, multi-disciplinary team-based care.

5. Better coordination with other sectors (SHORT TERM)

Coordination with other sectors will be important in improving health services for people with intellectual disability in a holistic, person-centred way. In particular, greater coordination is required with the disability, education, employment, housing, and other relevant sectors. Steps need to be taken to help ensure seamless, integrated health care and disability support services. These could include:

- making the NDIS system more accessible for users to navigate;
- enabling and supporting better linkages between health care and NDIS providers; and
- increasing the focus of the NDIS on optimising health outcomes.

6. Support for people with intellectual disability and their families (SHORT TERM)

Support for people with intellectual disability and their families is critically important in improving the health of this vulnerable group. Recommended areas of focus include:

- initiatives to lessen the challenges for people with intellectual disability and their families in navigating the health system;
- harnessing their voices in informing providers' interactions with, and treatment of, people with intellectual disability;
- increasing the focus on supported decision making for people with intellectual disability, and valuing the role of their families in achieving this; and
- improving the health literacy of people with intellectual disability and their families, to help enable them to advocate for their needs.

B. Better support for health care professionals to provide better care for people with intellectual disability

7. Curriculum development in Medical and Nursing Schools (MEDIUM TERM)

Medical professionals generally have minimal training in intellectual disability health care (an average of 2.6 hours in medical degrees), and there is variability in the amount and specificity of content in nursing degrees. As proposed by Minister Hunt, a key part of the National Roadmap will be working with the Deans of Medical Schools on curriculum development to improve the education of doctors to better support people with intellectual disability.

It is also proposed that the Australian Government and other key stakeholders work with Nursing Schools on curriculum development, noting the key role that nurses also have in providing care for people with intellectual disability.

8. Primary Care Enhancement Program (SHORT TERM)

As agreed at the 2 August 2019 Roundtable, the Primary Care Enhancement Program proposed jointly by the Council for Intellectual Disability and Inclusion Australia, would form an initial element of the National Roadmap. The program will be developed in four PHN lead sites over four years, with a view to national rollout across all PHN regions. It will:

- build on existing infrastructure and focus on the needs of people with intellectual disability;
- be comprised of the following key components:

- training and support for the PHN lead sites from specialist intellectual disability health centres and local intellectual disability advocacy organisations;
- development of national resources, including a training module for PHN staff, NDIS linkage tools, resources for GPs, and health promotion information for people with intellectual disability and their families; and
- evaluation of the initial rollout of program in the PHN lead sites, prior to national rollout;
- include a focus on Aboriginal and Torres Strait Islander people, and other vulnerable and marginalised populations; and
- include the development of an innovative model to achieve seamless and connected integration of primary health care services for people with intellectual disability.

9. Provider education and training (MEDIUM TERM)

A range of initiatives is recommended, to better educate and train health service providers in caring for people with intellectual disability:

- embedding training within all Specialist Training Programs, including working with the Medical Colleges to develop curriculum for a sub specialty or the like in intellectual disability (particularly in the care of adults), and improving training for allied health professionals, dentists and pharmacists;
- supporting providers in the use of multidisciplinary models of team based care;
- identifying 'champions' within Medical Schools, to promote the importance of better care for people with intellectual disability;
- drawing upon the knowledge and experience of health professionals with expertise in intellectual disability, to better educate and train nurses in caring for people in this population, across health care settings;
- drawing upon the lived experience of people with intellectual disability and their families, in better educating health care providers; and
- training providers in using visuals and simple language to communicate more effectively with people with intellectual disability, about health issues and treatments.

10. Network of Centres of Excellence on Intellectual Disability (LONG TERM)

It is proposed that a national network of Centres of Excellence on intellectual disability be established, with the potential to have at least one Centre in each state and territory. The network would:

- maintain, and in the longer term, expand on those that already exist in NSW, Victoria, Queensland and South Australia;
- work in partnership with people with intellectual disability;
- be accessible to, and serve as a hub of expert advice for the health workforce, particularly GPs, nurses, and allied health practitioners, and for PHNs and disability services; and
- facilitate the delivery of clinical services in collaboration/ consultation with existing services, and facilitate access to urgent care for people with intellectual disability.

C. Research, data and measurement to support continuing improvement (MEDIUM TERM)

Research, data and measurement will also be a key platform for tracking the health outcomes of people with intellectual disability, and assessing the efficacy of initiatives to improve them.

Recommendations include:

- a focus on increasing the Australian evidence base on the health of people with intellectual disability;
- building a national data asset on the health of people with intellectual disability; and
- embedding an outcomes based focus, and using Patient-Reported Experience Measures and Patient-Reported Outcome Measures.

11. Other considerations

The Roundtable also identified a number of other considerations, which need to be incorporated in the National Roadmap, or taken into account in its implementation. These include:

- considering the needs of people with intellectual disability and their families in the development of all health policies and initiatives; and
- resourcing requirements for implementing the Roadmap.