



THE HEALTH OF PEOPLE WITH INTELLECTUAL DISABILITY

Budget and Federal election 2019

Commitments sought from Australian political parties

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OUR PROPOSALS IN TWO PAGES

The population

450,000 people in Australia have intellectual disability. With their close families, this is two million Australians.

Stark and costly health inequalities

Compared with the general population, people with intellectual disability experience:

- Over twice the rate of avoidable deaths: 38-53% potentially avoidable deaths.
- Twice the rate of emergency department and hospital admissions.
- Hospital admissions costing twice as much.
- Higher rates of physical and mental health conditions.
- Lower rates of preventative healthcare.

Take-up is low for the research validated Medicare annual health assessments for people with intellectual disability.

Health professionals face challenges communicating with people with intellectual disability, distinguishing health problems from the disability, and diagnosing complex health conditions. They generally have minimal training in intellectual disability health care (an average of 2.6 hours in medical degrees and no content in the majority of nursing degrees).

Action on these inequalities is called for by the COAG National Disability Strategy, the 5th National Mental Health and Suicide Prevention Plan, the UN Convention on the Rights of Persons with Disabilities and the effective implementation of the National Disability Insurance Scheme.

Action to date in Australia

NSW Health has led the way on specific initiatives to address the health inequalities faced by people with intellectual disability, including establishing a state-wide network of specialised intellectual disability health services to backup mainstream health services.

At the national level, action has been very limited and fragmentary.

Actions to take now

The research evidence is strong for two specific initiatives to be taken now. These would be complemented by a national inquiry to recommend a framework for further action.

Proposal 1 - Primary health enhancement program

Each of the 31 Primary Health Networks (PHNs) around Australia should be funded for a program to enhance the capacity of GPs and other primary health services.

Specialised nurses/allied health professionals would provide consultancy, training and resources to primary health services aimed at enhanced communication skills, preventative health, early diagnosis and treatment, cost effective services, effective use of programs such as My Health Record and Health Care Homes and collaboration with specialists, hospitals and the NDIS.

The PHN workers would also be a resource to people with intellectual disability and their families to link them to appropriate healthcare.

National resources would be developed to support the PHNs, including resources that could be incorporated into software used by GPs.

The cost of this proposal is \$13.6m a year plus evaluation \$1.3m.

Proposal 2 - Curriculum enhancement in medical and nursing schools

Develop proposed model curriculums for medical and nursing schools. Pilot and evaluate the curriculums in three medical and three nursing schools.

The cost of this proposal is up to \$8m over three years.

Savings from acting on Proposals 1 and 2

The central saving would be that people with intellectual disability would be healthier and lead better lives.

For Government, there are considerable financial savings:

- The cost of treatment of avoidable chronic and acute conditions.
- Hospitalisation costs. With people with intellectual disability currently experiencing elevated rates and costs of hospitalisations, improved primary care would lead to very large savings. We are preparing an estimation of these savings.
- Savings to the NDIS from reduced support needs – estimated at over \$100m a year.
- Gains for the economy from increased workforce participation by family carers and by people with intellectual disability themselves.

Proposal 3 - A national inquiry

The Australian Government should complement the above initiatives with an independent expert inquiry into the health of people with intellectual disability, with particular reference to health services within Commonwealth responsibility.

The inquiry would recommend a framework to remedy barriers to good health for people with intellectual disability including consideration of the Medicare Benefit Schedule, activity-based funding, medical specialist training, establishing a national data collection system and enhancing collaborative action with State/Territory health agencies and the NDIS.

The cost of the inquiry would be \$3m.

OUR PROPOSALS IN DETAIL

Our proposals address inequality for 2 million Australians

Approximately 450,000 people in Australia have intellectual disability.¹ With their close families, this makes up at least 2,000,000 Australians affected by the inadequate health care experienced by people with intellectual disability.

Our proposals have strong national support

Leading this campaign, Council for Intellectual Disability (CID) is representing Inclusion Australia (NCID), the national peak group for people with intellectual disability and their families.

The state members of Inclusion Australia are:

- Victorian Advocacy League for Individuals with Disability
- South Australian Council on Intellectual Disability
- Development Disability Western Australia
- Parent to Parent Queensland
- Speak Out Advocacy Tasmania
- NSW Council for Intellectual Disability

Other collaborators in the campaign are:

- Down Syndrome Australia
- The Australian Association of Developmental Disability Medicine
- The Department of Developmental Disability Neuropsychiatry UNSW

Stark health inequalities

The research shows the following inequalities for people with intellectual disability when compared with the general population:²

- 2.5 times the number of health problems.
- 38 – 53 percent potentially avoidable deaths compared with 17 percent for the general population.
- Early indications of future increased ill-health such as obesity and psychiatric disorder.
- Under-diagnosis of chronic and acute health conditions.

¹ See accompanying research summary and note increase in Australian population since 2017.

² See accompanying research summary and, in relation to rates of potentially avoidable deaths, Trollor J, Srasuebku and Howlett S (2017) [bmjopen.bmj.com/content/7/2/e013489](https://doi.org/10.1136/bmjopen-2017-013489) and Office of the Public Advocate (Qld) (2016), Upholding the right to life and health: a review of the deaths in care of people with disability in Queensland www.justice.qld.gov.au/_data/assets/pdf_file/0008/460088/final-systemic-advocacy-report-deaths-in-care-of-people-with-disability-in-Queensland-February-2016.pdf

- Higher rates of potentially modifiable cardiometabolic risk factors.
- Under-representation of consultations with GPs addressing physical and preventative health issues.
- Significantly less likely to be prescribed preventative health medications.
- Higher prescription of psychotropic medication, even after allowing for elevated incidence of mental illness.
- Double the usage of emergency departments and hospital admissions with each admission costing twice as much.
- Much higher rates of potentially preventable hospitalisation.
- Five times more likely to experience mental health admissions of over a year and three times as likely to be admitted more than three times a year.
- 1.6 times more face to face contacts with community mental health services and each contact is 2.5 times longer.
- Die many years earlier, 27 years in one large Australian study.

In 2008, the National Health and Hospitals Reform Commission reported that people with intellectual disability face “stark health inequalities”.³

Factors contributing to these inequalities include:⁴

- Communication challenges between health professional and person with intellectual disability.
- Diagnostic overlay - the assumption that symptoms are part of the intellectual disability rather than a health condition that requires treatment.
- Workforce challenges - inadequate workforce training in communicating with and addressing complex health care needs of people with intellectual disability.
- The lack of targeting of people with intellectual disability in health promotion and prevention strategies.
- Inadequate uptake of Medicare annual health assessments.
- The lack of societal value attached to people with intellectual disability.
- Inadequate focus on healthy lifestyles and promoting good health in disability support services.
- Poverty and other social disadvantage.

³ National Health and Hospitals Reform Commission (2008) A Healthier Future for All Australians, Interim Report, pages 54-55

⁴ National Health and Hospitals Reform Commission (2008); NSW Ombudsman, periodic reports on reviewable deaths of people with disability www.ombo.nsw.gov.au/news-and-publications/publications/annual-reports/reviewable-deaths; Disability Services Commissioner Victoria, Review of disability service provision to people who have died 2017-18 www.odsc.vic.gov.au/2018/12/20/poor-disability-support-practices-highlighted-in-review-of-deaths-of-people-with-disabilities-in-victoria/; Emerson E and Hatton C (2007), Poverty, socio-economic position, social capital and the health of children and adolescents with intellectual disabilities in Britain: a replication, 51 JIDR Part 2, 866-874

National policy framework

A range of key documents support national action on the health of people with intellectual disability. These include:

UN Convention on the Rights of Persons with Disabilities 2006 (CRPD)

People with disability “have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability”. This includes “the same range, quality and standards of free or affordable health care as provided to other persons” and health services needed because of their disabilities. (Article 25)

National Disability Strategy 2010-2020 (COAG 2011)

The COAG strategy is intended to guide policy and program development by all levels of government and actions by the whole community. The strategy commits all government to six key outcomes, including that people with disability attain the highest possible health and wellbeing outcomes throughout their lives.

To achieve this outcome, the strategy specifies policy directions including:

- All health services being able to meet the needs of people with disability.
- Timely, comprehensive and effective prevention and early intervention health services for people with disability.
- Universal health reforms and initiatives addressing the needs of people with disability, their families and carers.

National Disability Insurance Scheme (NDIS)

There is a strong nexus between the complementary responsibilities of the NDIS and health services. If people with intellectual disability have adequate disability supports, they may be less likely to develop health problems and conditions may be much easier to treat. If people do not receive appropriate health services, their disability support needs may be much greater and more expensive to meet.

There also need to be strong national and local collaborative relationships between the health and NDIS systems to address demarcations between the responsibilities of the two systems.

5th National Mental Health and Suicide Prevention Plan 2017

The Plan notes that people with intellectual disability are two to three times more likely to have a mental illness than the general population but encounter significant barriers to treatment and often have complex needs that require a coordinated approach across multiple service systems.

The Plan states that actions in the Plan and related activity by governments require specific and appropriate application to diverse groups, specifically including people with intellectual disability.

The cost of not acting

Our predominant concern is the human cost to people with intellectual disability of not meeting their health care needs. There is also a human cost to family members who support people with intellectual disability.

For government, there is considerable financial cost from not acting on the health inequalities experienced by people with intellectual disability:

- The cost of treatment of avoidable chronic conditions.
- The cost of treatment of avoidable acute conditions.
- Avoidable hospitalisation costs.
- The cost to the NDIS of increased disability support needs flowing from poor health.
- The cost to the economy of reduced workforce participation by family carers and by people with intellectual disability themselves.

See below for an estimation of savings to Government from acting on our proposals.

Action to date in Australia

Action by State and Territory governments

Over the last decade, NSW Health has taken substantial and specific action to address the health care needs of people with intellectual disability, in particular:

- The Framework to Improve the Health Care of People with Intellectual Disability 2012.⁵
- Development of a state-wide network of specialised intellectual disability health services in Local Health Districts to provide specialist backup to mainstream health services. There is now funding for intellectual disability health teams in six LHDs and outreach health professionals in the other LHDs.
- Funding a chair in intellectual disability mental health at UNSW.⁶
- Establishment of an Intellectual Disability Health Network in the Agency for Clinical Innovation.⁷

⁵ www.health.nsw.gov.au/disability/Publications/health-care-of-people-with-ID.pdf

⁶ 3dn.unsw.edu.au/

⁷ www.aci.health.nsw.gov.au/networks/intellectual-disability

Action in other States has been more modest but does include specialist research, education and clinical centres in Victoria, Queensland and South Australia.⁸

We argue that action in NSW is an exemplar that should drive action in other States and Territories and at a national level.

Action by the Australian Government

To date, there has only been fragmentary action at the national level, most notably including:

- Introduction into Medicare of annual health assessment items for people with intellectual disability (2007).
- Specific reference to people with intellectual disability in a small number of health policies and guidelines, for example the 5th National Mental Health and Suicide Prevention Plan and some mental health guidelines for Primary Health Networks.
- Funding of the National Roundtable on the Mental Health of People with Intellectual Disability 2013 and of Accessible Mental Health Services for People with an Intellectual Disability, A Guide for Providers 2014.

These initiatives have occurred after concerted advocacy by the intellectual disability sector.

The annual health assessment items were a positive initiative. Annual health assessments for people with intellectual disability have strong research validation for revealing previously undiagnosed health conditions and leading to health promotion and other targeted action on health needs.⁹ However, for want of a program within the health system to drive uptake, uptake was very low. Three years after the items were introduced, Medicare data showed the take up was only 7510 of the over 400,000 people with intellectual disability in Australia. The items were then absorbed into more generic assessment items so that data on take-up by people with intellectual disability has not been available. A very much higher rate has been achieved in England and Wales with a strong national program to promote take up and quality of the assessments.¹⁰

⁸ gcidd.centre.uq.edu.au/
www.cddh.monashhealth.org/
www.svhm.org.au/our-services/departments-and-services/v/victorian-dual-disability-service
dhs.sa.gov.au/services/disability-services/centre-for-disability-health

⁹ Lennox N, Bain C, Rey-Conde T, Purdie D, Bush R and Pandeya N (2007), Effects of a comprehensive health assessment programme for Australian adults with intellectual disability: a cluster randomised trial, *Int J Epidemiol.* 2007 Feb;36(1):139-46; Robertson J, Roberts S, Emerson D, Turner S and Greig R (2011), The impact of health checks for people with intellectual disabilities: a systematic review of evidence, 55 *JIDR*, part 11, 1009.

¹⁰ assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/647512/Auditing_health_checks_tool_for_people_with_learning_disabilities.pdf

Primary Health Networks (PHNs) are expected to particularly focus on people “at risk of poor health outcomes”¹¹. However, the focus of PHNs and their predecessor Medicare Locals on people with intellectual disability has been modest. See Appendix 1.

Unlike for various other at risk groups and priority issues, PHNs and Medicare Locals have not received specific funding targeted at people with intellectual disability.

Priority actions now for the Australian Government

In the 2019 budget or, failing that, the federal election, we seek commitment to three proposals:

1. A specific funded program to enhance the capacity of GPs and other primary health care services to respond to the needs of people with intellectual disability.
2. Development, piloting and evaluation of curriculum enhancements in university medical and nursing schools.
3. A national inquiry into the health of people with intellectual disability.

There is a clear evidence base to act immediately on Proposals 1 and 2. A national inquiry will provide the basis for a fuller framework of action.

Proposal 1 - A primary health enhancement program

It is clear from the research that the skills and focus of GPs and other primary health care services on people with intellectual disability needs considerable enhancement.

We propose a national program focused on enhancement of health care to people with intellectual disability by GPs and other primary health care services. In line with the existing roles of Primary Health Networks (PHNs), the proposed program would logically be provided through them.

The functions of the program

In summary, the functions of the program would be:

- Enhancing the skills of the primary health workforce in communication, diagnosis and treatment with people with intellectual disability.
- Ensuring people with intellectual disability have equitable access to health prevention and promotion.
- Promoting use of Medicare annual health assessments.

¹¹ www.health.gov.au/internet/main/publishing.nsf/Content/PHN-Home

- Ensuring people with intellectual disability have effective access to all PHN programs and other relevant healthcare initiatives.
- Supporting primary health services to provide cost effective healthcare.
- Facilitating access to an appropriate GP for people with complex needs.
- Facilitating coordinated local responses between primary health services and:
 - Other health services including hospitals and medical specialists who have expertise in intellectual disability health.
 - The NDIS and other community services.

Components of the program

1. **Central leadership** by the Australian Department of Health with a reference group from the intellectual disability consumer sector, intellectual disability health leaders, relevant professional colleges and other leading primary healthcare bodies, and the NDIS.
2. **A program in each PHN** staffed by nurses/allied health professionals skilled in primary care and intellectual disability. There would be an average of three health professional staff in each PHN. (PHNs range in population from 60,000 to 1.7m and have widely varying geographic sizes and population demographics.)

PHN staff would carry out the functions above by roles including: practice visits; education programs; establishing pathways to specialised services; consultancy to GP practices, people with intellectual disability and their families and disability services; establishing local information systems; and coordinating a local special interest group and reference group.

3. **Development of national resources** including: a training module for PHN intellectual disability staff; resources to be included in GP software; guidelines for quality primary care; NDIS linkage tools; and health promotion information for people with intellectual disability and their families.
4. **Evaluation** of the effectiveness of the program with recommendations for enhancement of effectiveness.

See Appendix 2 for a more detailed list of the functions of the proposed primary health enhancement program, the proposed roles of PHN staff and examples of national resources that should be developed.

Table 1: Costing of Proposal 1

	Annual costs (\$)
Central leadership including costs for reference group ¹³ (Assuming largely absorbed by Department of Health staffing)	100,000
Programs in PHNs	
Salaries and on costs for an average of 3 health professional staff in each PHN (31 x 3 x \$110,000) ¹⁴	10,230,000
Consultancy by people with intellectual disability (31 x \$10,000)	310,000
Administration costs	1,000,000
Education programs	500,000
Sub total programs in PHNs	12,040,000
National resource production	1,500,000
Total	13,640,000

An additional \$1,300,000 should be committed to evaluating the program over three years.

Proposal 2 - Medical and nursing school curriculum enhancement

The focus on people with intellectual disability in university medical and nursing schools is very low:

- A median of 2.6 hours compulsory content across 12 medical schools (with one university standing out with 12 hours).¹²
- No intellectual disability content in 52 percent of nursing schools and very limited content overall.¹³

We propose development, piloting and evaluation of an evidence-based toolkit for medical schools and a similar toolkit for nursing schools. Each toolkit would include:

- Suggested core intellectual disability physical and mental health curriculum content.
- Evidence-based teaching methods including inclusive teaching by people with intellectual disability and their families.

¹² Trollor J, Ruffell B, Tracy J, Torr J, Durvasula S, Iacono T, Eagleson C and Lennox N (2016), intellectual disability health content within medical curriculum: an audit of what our future doctors are taught [bmcmededuc.biomedcentral.com/articles/10.1186/s12909-016-0625-1](https://doi.org/10.1186/s12909-016-0625-1)

¹³ Trollor J, Eagleson C, Turner B, Salomon C, Cashin A, Iacono T, Goddard L and Lennox N (2016), intellectual disability health content within nursing curriculum: an audit of what our future nurses are taught [www.sciencedirect.com/science/article/pii/S026069171630106X](https://doi.org/10.1016/j.scimed.2016.06.006)

- Relevant resources.
- Suggested ways to incorporate this content into existing undergraduate/preregistration curriculums.

The toolkits would be piloted and evaluated in three nursing schools and three medical schools around Australia. In light of the evaluation, the toolkits would be refined with a view to national rollout.

We ask the Australian Government to pay for the project and provide strong support for take-up by universities.

Table 2: Costing of Proposal 2

	Cost over 3 years (\$)
Development of two online toolkits, including refinement in light of evaluation	800,000
Piloting and evaluation - \$1.2 million per university per course. (If universities provided strong personnel support for the piloting, this amount might be reduced to \$600,000 per university per course)	7,200,000
Total	8,000,000

Savings from acting on the Proposals 1 and 2

The central saving would be that people with intellectual disability would be healthier and lead better lives.

For Government, there are considerable potential financial savings:

- The cost of treatment of avoidable chronic conditions.
- The cost of treatment of avoidable acute conditions.
- Hospitalisation costs.
- Savings to the NDIS from reduced support needs including reduced physical support needs and challenging behaviour.
- Gains for the economy from increased workforce participation by family carers and by people with intellectual disability themselves.

It is difficult to quantify these savings. We are developing an estimate of potential savings in hospitalisation costs.

We estimate potential **savings to the NDIS at over \$100m a year**. We have calculated this on the basis of improved health of people with intellectual disability leading to a 1 percent reduction in their disability support costs. We have based this projection on the average NDIS funding package for participants with intellectual

disability in NSW (the State where the NDIS is closest to full roll out). This average package is \$85,000. We have projected from that to full rollout spending on packages for people with intellectual disability and then calculated 1 percent of that amount to be \$109.48m a year across Australia. See Appendix 3 for details of these calculations.

Proposal 3 - A national inquiry on the health care of people with intellectual disability

The Australian Government should complement the above two initiatives with an independent expert inquiry into the health care of people with intellectual disability with particular reference to health services within Commonwealth responsibility. The inquiry would conduct public consultations, review the current evidence for best practice and recommend a framework of action to provide accessible, high quality health care to people with intellectual disability.

The inquiry should address physical and mental health across the lifespan including:

- Current access to health care for people with intellectual disability and barriers to access.
- Current health outcomes for people with intellectual disability and barriers to positive outcomes.
- Strategies required to remedy barriers and deliver quality health care, including consideration of the following:
 - The Medicare Benefit Schedule.
 - Activity based funding and other health funding models.
 - Specialist training within relevant health professions.
 - Inclusion in all relevant Commonwealth initiatives, for example My Health Record and the Practice Improvement Program for general practice.
 - Inclusion in all relevant Commonwealth health policies.
 - The roles of national health agencies such as the Australian Commission on Safety and Quality in Health Care and the National Mental Health Commission.
 - Implementation of the 5th National Mental Health and Suicide Prevention Plan.
 - Promoting collaborative action between Commonwealth and State/Territory health agencies.
 - Promoting collaborative action between health services and the NDIS and other community support systems.
- Establishing a national data collection system.
- Cost benefit analysis of action and inaction.

The head of the inquiry should be a person with health system expertise and sensitivity to the health needs of people with intellectual disability. The head should be supported by a health actuary and a secretariat of policy, research and

administrative staff. There would also be a reference group with similar makeup to that proposed above for the Primary Health Enhancement Program.

The inquiry should be funded \$3m over one year.

Appendix 1 – The limited focus of Medicare Locals and Primary Health Networks on people with intellectual disability

Medicare Locals had a mandate to identify groups who were missing out on health services and coordinate services to address these gaps.¹⁴ With funding from the then Department of Health and Ageing, the Council for Intellectual Disability (CID) produced and distributed fact sheets for Medicare Locals and local disability groups to assist them to work together. These fact sheets suggested practical strategies that Medicare Locals could take to include people with intellectual disability in their consultative and planning processes and in their programs.

In 2014, CID conducted an audit of action by Medicare Locals on the health of people with intellectual disability. Of the 61 Medicare Locals, 21 responded to this audit and it would be reasonable to postulate that those who responded were more likely to have something positive to report than those who did not. From the 21 Medicare Locals that responded:

- Only four said they included intellectual disability groups in their governance and consultation systems.
- Only eight said they identified the needs of people with intellectual disability in their needs assessment and planning.
- Only seven said they were ensuring new programs included a focus on people with intellectual disability.

In 2015, Medicare Locals were replaced by Primary Health Networks. 31 PHNs were established, “to increase the efficiency and effectiveness of medical services for patients, particularly those at risk of poor health outcomes, and to improve coordination of care to ensure patients receive the right care in the right place at the right time”.

The Australian Government specified seven key priorities for targeted work by PHNs. These were mental health, Aboriginal and Torres Strait Islander health, population health, health workforce, digital health, aged care, and alcohol and other drugs.¹⁵

In 2016, the Department of Developmental Disability Neuropsychiatry at UNSW searched the needs assessments of PHNs for acknowledgements of specific or unmet health needs of people with intellectual disability. Out of 24 PHNs whose needs assessments were available online, 15 referred specifically and mainly briefly to the health needs of people with disability. Only six of these included specific mentions of people with intellectual disability as having unmet or specific needs.

In January 2019, CID scanned the websites of the 31 PHNs searching for references to resources and actions in relation to people with intellectual disability. 29 of 31 websites mention “disability” but mainly in the context of information sessions in relation to the NDIS. Around 25 percent of websites include links to other disability information.

¹⁴ meteor.aihw.gov.au/content/index.phtml/itemId/517967

¹⁵ www.health.gov.au/internet/main/publishing.nsf/Content/PHN-Background

One standout exception is Central and Eastern Sydney PHN, which is a good source of information about disability services provided by other agencies and has employed a worker with a specific focus on enhancing the capacity of primary health care services to work with the NDIS. CESP HN has a history of focus on people with intellectual disability, going back to a program to enhance primary health care in the Central Sydney GP Network.

In our review of PHN websites, CID looked at services funded under the Commonwealth Primary Mental Health Care initiative since – following strong advocacy from us – the Department of Health included some references to people with intellectual disability in guidelines for this program including specifically listing them in a list of currently underserved groups. The Department reported to us that it had encouraged PHNs to be inclusive of people with intellectual disability and to contact CID and/or Professor Julian Trollor for further information in relation to the mental health needs of people with intellectual disability.¹⁶

Neither Professor Trollor nor CID received any approach from a PHN apart from Central and Eastern Sydney. From our website reviews, only three PHNs appeared to fund a mental health service that includes people with intellectual disability in its underserved target groups. One PHN specifically states that its psychological therapies program is not open to people with intellectual disability.

¹⁶ Letter from Anthony Millgate, Assistant Secretary, Mental Health Services Branch, Department of Health dated 29 August 2016

Appendix 2 – Functions and roles in the proposed primary health enhancement program

Functions of the Program

- Enhancing the skills of the primary health workforce in communication, diagnosis and treatment including an understanding of substitute consent requirements and legal and disability practice requirements for chemical restraint and other restrictive practices.
- Ensuring that people with intellectual disability have equitable access to health prevention and health promotion programs.
- Promoting take-up and quality of Medicare annual health assessments.
- Enhancing the skills of the primary health workforce in early childhood development surveillance, developmental referrals and other appropriate health support for young children.
- Ensuring that the range of programs provided or funded by PHNs are inclusive of people with intellectual disability.
- Ensuring that the Health Care Homes initiative is workable for and inclusive of people with intellectual disability.
- Ensuring that the local Health Pathway is inclusive of people with intellectual disability.
- Facilitating access to an appropriate GP for people with complex healthcare needs.
- Ensuring non-discriminatory healthcare to people with intellectual disability.
- Promoting autonomy in healthcare decisions for people with intellectual disability with support and input from families and advocates as needed.
- Promoting effective use of the My Health Record system and other tools such as CID's My Health Matters.¹⁷
- Supporting primary health care services to provide cost efficient services to people with intellectual disability.
- Promoting coordinated consumer focused practices for hospitalisations – admissions, treatment and disability support in hospital and discharge arrangements.
- Promoting coordination and seamless complementarity of roles between primary healthcare services and funded NDIS services including the role of primary health services in supporting people with intellectual disability to access the NDIS, seek behaviour support services and raise complaints about abuse, neglect or inadequate support services.
- Promoting coordination and seamless complementarity of roles between primary healthcare services and mainstream services such as public housing and child protection.
- Promoting linkages between primary health services and specialised intellectual disability health services and other medical specialists with expertise in intellectual disability health care including joint consultations and a framework for coordinating primary and specialised healthcare.

¹⁷ www.nswcid.org.au/my-health-matters.html

Roles of staff in Primary Health Networks

- Practice visits to GPs and other primary health care services.
- Local education programs for primary health services and the intellectual disability sector.
- Establishing pathways to specialised intellectual disability health services.
- Identifying primary and secondary health services with expertise in intellectual disability.
- Being a consultancy resource to primary health services including those funded by the PHN.
- Being a consultancy resource to people with intellectual disability, their families and support providers in relation to health promotion and accessing primary healthcare services.
- Being a consultancy resource to local mainstream services.
- Establishing local information systems so that primary health services and the community can access health care information including local implementation of national resources.
- Promoting quality general practice through the Practice Improvement Program.
- Coordinating an intellectual disability health special interest group in the PHN.
- Coordinating a local reference group from the intellectual disability community including people with intellectual disability, family members, advocates and disability providers.
- Promoting inclusion of people with intellectual disability in PHN needs assessments and consultative mechanisms.

Examples of national resources to be developed

- A training module to ensure high level skills and values in the PHN intellectual disability staff.
- Resources on intellectual disability health to be included in software used day to day by GPs such as Medical Director and Best Practice.
- Uniform national guidelines on prescribing with significant focus on prevention of cardiometabolic disease and appropriate prescribing of psychotropic medication.
- Resources for people with intellectual disability, their families and support providers about health promotion and prevention and other primary health care.
- Comprehensive targeted information for GPs about NDIS eligibility assessments and processes (building on existing information developed by Council for Intellectual Disability and Central and Eastern Sydney PHN).¹⁸
- Incorporating data collection in relation to people with intellectual disability into data extraction tools such as POLAR and Pencil.

¹⁸ www.nswcid.org.au/my-health-matters-gp-resources.html
www.nswcid.org.au/my-health-matters-gp-resources.html

Appendix 3 – Calculation of projected savings to the NDIS from Proposals 1 and 2

On 30 September 2018, there were 92,199 NDIS participants in NSW with plans. 28 percent (25,816) of these had a primary intellectual disability. The average plan for a person with primary intellectual disability was approximately \$85,000.¹⁹

At full rollout, the bilateral agreement between the Commonwealth and NSW anticipates 140,000 participants.²⁰ 28 percent of this is 39,200.

Therefore, the likely total cost to the NDIS of plans for people with a primary intellectual disability in NSW is 39,200 x \$85,000 = \$3.332 billion.

If our proposed primary health enhancement and curriculum enhancement programs reduce disability support costs by 1 percent, this would be a saving to the NDIS in NSW of \$33.32 million a year.

We can extrapolate this nationally on the basis of the national projected figure of 460,000 total participants at full rollout.²¹

This would be total potential savings to the NDIS of \$109.48m a year.

Notes:

1. The 28% intellectual disability figure is very conservative as it does not include people with a secondary intellectual disability:²²
 - a. People with low functioning autism. We would suggest that people with autism and higher support needs would mainly be people with secondary intellectual disability. 29 percent of NDIS participants in NSW have autism as their primary disability.
 - b. Many of the people with developmental delay (4 percent of participants), global developmental delay (1 percent) and cerebral palsy (5 percent).
2. On the other hand, the further participants yet to come into the scheme in NSW will tend to be people with lower support needs and therefore have packages smaller than \$85,000.

¹⁹ National Disability Insurance Agency, Report to the COAG Disability Reform Council for quarter one 2018-19 www.ndis.gov.au/about-us/publications/quarterly-reports See Appendix F, Tables F.1, F.6 and F.10.

²⁰ www.ndis.nsw.gov.au/wp-content/uploads/2015/07/Bilateral-Agreement-between-the-Commonwealth-and-New-South-Wales-2.pdf

²¹ www.ndis.gov.au/understanding/what-ndis

²² National Disability Insurance Agency, Report to the COAG Disability Reform Council for quarter one 2018-19 www.ndis.gov.au/about-us/publications/quarterly-reports