

COMMUNIQUE

Recommendations from the National
Roundtable on the Mental Health of
People with Intellectual Disability 2018



UNSW
SYDNEY



DEPARTMENT OF
DEVELOPMENTAL
DISABILITY
NEUROPSYCHIATRY



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Ombudsman
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FOREWORD

“We aren’t nobodies. We are someone important, just like you.”

“It would be a very different world if we put the lived experience and health of people with intellectual disability at the centre of our discussions.”

“Please take today seriously as a chance to make a difference in the lives of people with intellectual disability.”

Excerpts from keynote address

Mr Michael Sullivan,

Vice Chair, Council for Intellectual Disability

Australians with intellectual disability experience very high rates of mental ill-health, and multiple barriers to effective mental health care. Definitive action is required to address this issue. Doing so will help realise the right of people with intellectual disability to the enjoyment of the highest attainable standard of mental health. This Communiqué represents the response of sector leaders to the mental health needs of people with intellectual disability. It contains a series of practical Recommendations for improving the mental health system for people with intellectual disability. As such, these Recommendations represent the current thinking about how to improve the situation in Australia. Implementation of the Recommendations is a corporate responsibility. We encourage you and other sector representatives to engage with the Recommendations and to actively seek opportunities to lead initiatives as outlined in this Communiqué.

Julian Trollor

Professor and Head, Department of Developmental Disability Neuropsychiatry

Chair of Intellectual Disability Mental Health

School of Psychiatry, UNSW Sydney, Australia

INTRODUCTION

This document presents a series of Recommendations under eight Elements of an effective mental health system for people with intellectual disability. These Recommendations were collated from the responses of sector leaders to the mental health needs of people with intellectual disability. The responses were articulated at the second National Roundtable on Intellectual Disability Mental Health held on 27 March 2018 at UNSW Sydney.

Eight Elements of an effective mental health system for people with intellectual disability were agreed at the first Roundtable event in 2013. These Elements were used as a framework for generation of Recommendations for further action at the second National Roundtable. The current communiqué presents a summary of each of the top three Recommendations developed by 2018 Roundtable participants for action within each Element. A more detailed description of each Recommendation is presented in [Appendix 1](#), together with suggested pathways to assist stakeholder implementation.

The second National Roundtable on Intellectual Disability Mental Health was a major research translation event of a National Health and Medical Research Council (NHMRC) funded Partnerships for Better Health Project “Improving the mental health outcomes of people with intellectual disability” (APP 1056128). It brought together 130 lead clinicians, academics and sector representatives from around Australia (see [Appendix 2](#) for a list of attendees). The Roundtable sought to engage sector leads at a national and state level to raise awareness of the mental health needs of people with intellectual disability, generate a set of clear and actionable Recommendations for the sector, and to act as a catalyst for ongoing improvement in mental health services and outcomes for people with intellectual disability.

This National Roundtable was organised by the Department of Developmental Disability Neuropsychiatry, UNSW Sydney in collaboration with the Council for Intellectual Disability and research partners. Important background about intellectual disability mental health, the NHMRC research partnership which informed the 2018 Roundtable, the eight Elements, and the National Roundtable methodology is presented on pages 3–13. Further detail about the Roundtable, NHMRC Partnerships Project and results of the pre-roundtable survey are included in [Appendix 2](#).

OVERVIEW

The following diagram summarises the three top Recommendations in each of the eight Elements of an effective mental health system for people with intellectual disability. Each Recommendation is briefly described on pages 4–11 and in more detail in [Appendix 1](#).





Element 1: INCLUSION

The mental health needs of people with intellectual disability are specifically considered and accommodated in all mental health initiatives.

Recommendation 1:

Implement a co-design approach to planning, services and evaluation



A National Guide to Co-design would enable the development of mental health services that are responsive to people with intellectual disability. Its development and implementation should be led or supported by key national bodies such as the National Mental Health Commission, the Mental Health Stakeholder Group to the Australian Government Department of Health, and the Mental Health Principal Committee of COAG. The guide should be developed with people with intellectual disability, family members, advocates, and intellectual disability mental health professionals.

Roundtable participants suggested a strategy for development of the guide.

Recommendation 2:

All state/territory mental health plans should address inclusion of people with intellectual disability



Specific inclusion of people with intellectual disability in state/territory mental health plans is necessary to ensure their distinct mental health needs are acknowledged and met. Where this has occurred to date, the inclusion of action items on intellectual disability mental health has been a driver for key initiatives and enhancements. All state/territory plans should therefore include a section on intellectual disability, and/or have specific references and actions throughout the plan.

Roundtable participants suggested a strategy for implementation of this Recommendation.

Recommendation 3:

Establish appropriate support and funding models for primary care



The primary health sector currently struggles to respond adequately to the needs of people with intellectual disability and mental health problems. Development and incremental refining of models of care would lead to improvements in care. Primary Health Networks (PHNs) could lead enhancement of capacity and skills in primary care. Medicare Benefits Schedule (MBS) items could be revised to recognise the complexity of diagnosis and treatment, and the time health professionals need to spend with a person with intellectual disability and other informants; the current MBS review may provide scope to address this issue. With appropriate resourcing, the Health Care Homes model also has substantial potential for people with intellectual disability.

Roundtable participants suggested a strategy for implementation of this Recommendation.



Element 2: PREVENTION AND TIMELY INTERVENTION

People with intellectual disability and their families receive education and support to prevent, and to obtain early and timely assistance for mental illness.

Recommendation 1:

Implement competencies in intellectual disability mental health in health, disability, justice and education sectors nationally



Staged
2019–2021

Competencies in intellectual disability mental health describe core attributes of professionals and provide roadmaps and tools for professional development in this field. Lack of skills and confidence has been repeatedly demonstrated in key professional groups and contributes to an inability to meet the mental health needs of people with intellectual disability. Competencies should be developed and implemented for each of the above sectors by adapting existing [competency frameworks](#) and [toolkits](#).

[Roundtable participants suggested a strategy for implementation of this Recommendation.](#)

Recommendation 2:

Provide health promotion and information on early signs of mental ill-health to young people with intellectual disability



Staged
2019–2020

Presently, people with intellectual disability are not specifically included in health promotion. Information on early signs of mental ill-health and what to do about them is not readily accessible to people with intellectual disability. People with intellectual disability should specifically be included in health promotion initiatives, and accessible information about early signs should be developed for people with intellectual disability in order to support this group to improve their mental health. Roundtable participants recommended that this work is undertaken in partnership between consumers, advocates, disability and health service providers, and academic leads.

[Roundtable participants suggested a strategy for implementation of this Recommendation.](#)

Recommendation 3:

Develop scalable, evidence-based tools to support health professionals to deliver effective mental health care for people with intellectual disability



Staged
2019–2021

Clinicians lack awareness of available evidence-based tools to assist assessment and management of mental illness and related disorders in people with intellectual disability. Whilst many tools and links to resources have been developed, these need organisation and coordinated promotion. A web-based clearing house is required to disseminate information to enable professionals to deliver more effective mental health care to people with intellectual disability.

[Roundtable participants suggested a strategy for implementation of this Recommendation.](#)



Government agencies (departments, offices, agencies, commissions, etc.)



Peak & professional bodies



Advocates & people with intellectual disability



Services (human, health, education)



Academics



Element 3: ACCESS TO SKILLED SERVICES

All mental health services provide equitable access and appropriately skilled treatment to people with intellectual disability.

Recommendation 1:

Add positions in Local Health District (LHD) mental health services to build capacity and workforce skills in intellectual disability mental health

\$\$\$



Staged
2019-2021

People with intellectual disability are frequent users of mental health services but available evidence indicates poorly coordinated and inefficient care. Recently established clinical positions (including coordinator or clinical nurse consultant) have been pivotal in building workforce capacity and improving practice in intellectual disability mental health within LHD mental health services. Positions should be implemented in a coordinated manner, embrace principles of co-design, and be subject to strong evaluation.

Roundtable participants suggested a strategy for implementation of this Recommendation.

Recommendation 2:

Improve uptake and implementation of competency-based frameworks

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Staged
2019-2021

Element 3 work groups recognised the value of strong uptake and implementation of competency frameworks to improve clinical practice in intellectual disability mental health.

The strategy for implementation of this Recommendation was covered under  [Element 2, Recommendation 1](#).

Recommendation 3:

Develop and implement minimum mandated intellectual disability health content in curriculum of relevant disciplines

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Staged
2019-2021

Exposure to people with intellectual disability and their health needs during training will improve professionals' attitudes and capacity to address the mental health needs of this group. A striking deficit in this area is apparent in medical, nursing and psychology training, and should be addressed by adopting a co-production approach to the development of minimum mandated intellectual disability health content with a strong mental health focus in each discipline.

Roundtable participants suggested a strategy for implementation of this Recommendation.



Element 4: SPECIALIST SERVICES SUPPORT MAINSTREAM MENTAL HEALTH SERVICES

A national network of specialist intellectual disability mental health professionals is available to support mainstream mental health services – by provision of consultancy and training, and through research.

Recommendation 1:

Develop and implement a mental health policy framework for people with intellectual disability



Reliable inclusion of people with intellectual disability in national and state mental health policy is lacking. Urgent work is required to develop and implement a national mental health policy framework. This will ensure meaningful inclusion of people with intellectual disability within all state and national mental health policies.

Roundtable participants suggested a strategy for implementation of this Recommendation.

Recommendation 2:

Better support and coordination for people with intellectual disability at mental health triage and intake



Access to mental health services for people with intellectual disability should be improved by ensuring that each component of mental health services has a defined clinical pathway and capacity to respond to the needs of people with intellectual disability. Arguably the greatest need is within entry points to mental health services. The development of robust clinical pathways will require mapping of the clinical journey for a person with intellectual disability, awareness of clinical resources and supports, and the implementation of reasonable adjustments.

Roundtable participants suggested a strategy for implementation of this Recommendation.

Recommendation 3:

Ensure access to a specialist multidisciplinary team



Specialist multidisciplinary health teams are required for some people with intellectual disability because of their more complex mental health needs. Specialist multidisciplinary teams with a strong mental health component should be established. Uniformly available state and territory working groups, which include support for representation by consumers, carers and advocates, are necessary for the development of models and business cases for funding enhancements.

Roundtable participants suggested a strategy for implementation of this Recommendation.



Element 5: COLLABORATION

Ongoing joint planning by disability services, schools and mental health and other relevant services including (a) identification of referral and treatment pathways; and (b) a framework and capacity for collaborative responses where intellectual disability and mental health needs co-exist.

Recommendation 1:

Develop interdisciplinary practice in National Disability Insurance Scheme (NDIS) pre-planning and planning processes



Interdisciplinary practice in the pre-planning and planning of NDIS applications and supports is critical to ensuring cohesive supports for a person with intellectual disability. Interdisciplinary practice, particularly that which engages health or mental health professionals, has been limited by historical 'silos' between services. However, exemplars of good practice can be seen within highly specialised health and disability services, which offer either a multi- or interdisciplinary approach. Interdisciplinary practice is particularly important for people with complex support needs, including those with intellectual disability and co-occurring mental illness or challenging behaviour. Interdisciplinary practice frameworks and support must be developed to support interdisciplinary approaches by practitioners in the pre-planning and planning for NDIS participants. A key opportunity to get this right is within the National Disability Insurance Agency's (NDIA's) pathway for people with complex needs that is currently under development.

Roundtable participants suggested a strategy for implementation of this Recommendation.

Recommendation 2:

Build capacity and resources for interagency collaboration



Interagency collaboration benefits people with intellectual disability, professionals and services. However, there are currently limited resources to support and grow these collaborations. Lack of leadership due to devolution of state-based disability services risks regression of capacity in this area. Leadership is required in key agencies including NDIA, lead disability service providers, LHDs, PHNs, education, community services, and corrections to drive interagency resource development and implementation.

Roundtable participants suggested a strategy for implementation of this Recommendation.

Recommendation 3:

Through development of a co-design charter, ensure co-design of systems across levels of government to support people with intellectual disability and mental health needs



Adoption of co-design approaches across government and other agencies will ensure consumer input into services and systems development, in a way that better meets the mental health needs of people with intellectual disability. The development of a co-design charter would be strengthened if led by key national leads such as the National Mental Health Commission, which has led the development of similar charters in the past, as well as input from the Department of Social Services, Department of Health, people with intellectual disability and their families and advocates.

Roundtable participants suggested a strategy for implementation of this Recommendation.



Government agencies (departments, offices, agencies, commissions, etc.)



Peak & professional bodies



Advocates & people with intellectual disability



Services (human, health, education)



Academics



Element 6: **WORKFORCE DEVELOPMENT AND SUPPORT**

Training in intellectual disability mental health to minimum standards for front-line and other professional staff in disability services, schools and health services, particularly including primary health and mental health services.

Recommendation 1:

All education institutions to embed intellectual disability training, giving priority to health and mental health aspects



(See also  [Element 3: Recommendation 3](#))

Roundtable participants working on Element 6 suggested a broad strategy for implementation of this Recommendation involving a larger number of educational institutions.

Recommendation 2:

Include mental health in national standards for disability services



National standards relating to disability services (as have been articulated in the National Standards for Disability Services) specify what is expected of disability services. Yet, the specific obligations for disability services in interaction with other support systems such as health, is lacking. The current and future standards, in particular those developed by the NDIS Quality and Safeguards Commission, should specifically outline health-related aspects in such a way that the responsibility of disability services in this area is clear, and in a manner that strengthens the interagency imperative between disability and health services.

Roundtable participants suggested a strategy for implementation of this Recommendation.

Recommendation 3:

Upskill the mental health workforce to a minimum standard



(See also  [Element 2: Recommendation 1](#),  [Element 3: Recommendations 1-3](#);  [Element 6: Recommendation 1](#))

A broad range of professionals constitute the mental health workforce, with available evidence indicating lack of skill and experience in intellectual disability mental health in multiple sectors and professional groups. Opportunities should therefore be sought to develop minimum workforce training across multiple groups.

Roundtable participants suggested a broad strategy for implementation of this Recommendation.



Element 7: DATA

Collection and analysis of data that measures mental health needs, access to services, and outcomes of people with intellectual disability.

Recommendation 1:

Create ongoing linkage between state and federal datasets to enable examination of mental health outcomes and service use for people with intellectual disability

and



Recommendation 2:

Ensure NDIA & physical /mental health data exchange in order to aid planning and service improvement



Historical and current linkage projects in this area highlight the value of big data in understanding the health needs of, and informing service responses to, people with intellectual disability. High level leadership through COAG and agreement between NDIA, Australian Department of Health, the Australian Institute of Health and Welfare, and state and territory health counterparts will be required to ensure that appropriate data linkage capacity and interrogation of linked data is supported.

Roundtable participants suggested a strategy for implementation of this Recommendation.

Recommendation 3:

Map intellectual disability mental health services and their gaps nationally



Service mapping will assist the identification of gaps in intellectual disability health and mental health services. A dedicated project would be required to develop this map.

Roundtable participants suggested a strategy for implementation of this Recommendation.



Government agencies (departments, offices, agencies, commissions, etc.)



Peak & professional bodies



Advocates & people with intellectual disability



Services (human, health, education)



Academics



Element 8: MULTIPLE DISADVANTAGE

All Elements include specific focus on contributors to multiple disadvantage including poverty, isolated lives, alcohol and other drugs misuse, Indigenous status, culturally and linguistically diverse (CALD) background, and contact with the criminal justice system.

Recommendation 1:

Develop national minimum standard for universal services access for people with intellectual disability



A national minimum standard for access to health and human services for people with intellectual disability would reduce key barriers to accessing services.

Roundtable participants suggested a strategy for implementation of this Recommendation.

Recommendation 2:

Establish national guidelines for cross-agency collaboration for people with intellectual disability and mental health needs



(See also  [Element 5: Recommendations 1-3](#))

Cross-agency collaboration is recognised as critical to the provision of integrated supports for a person with intellectual disability and multiple disadvantage. The final goal of this Recommendation is the production and implementation of national guidelines for cross-agency collaboration at local, state and commonwealth levels.

Roundtable participants suggested a strategy for implementation of this Recommendation.

Recommendation 3:

Disability, justice and mental health guidance within the NDIS



(See also  [Element 5: Recommendation 2](#))

A greater understanding is required of the needs and factors that influence outcomes for people with intellectual disability who have contact with the justice system. Interagency collaboration is a concrete step likely to underpin quality service provision to people with intellectual disability who have contact with the justice system. An important initial step is to ensure that the NDIS pathway for people with complex needs has the capacity to cater to the needs of people who have contact with the justice system.

Roundtable participants suggested a strategy for implementation of this Recommendation.

BACKGROUND

Intellectual Disability Mental Health

People with intellectual disability represent about 1.8% of the Australian population, or approximately 450,000 individuals¹. The prevalence of mental ill-health is at least two to three times higher in people with intellectual disability compared to the general population². People with intellectual disability are more vulnerable to mental ill-health due to complex interrelationships between disability and other medical, social and psychological factors³.

Many people with intellectual disability experience a high degree of complexity and an atypical profile and presentation of mental illness⁴, thus requiring a high level of psychiatric expertise, and coordinated approaches between services. The poor health and mental health status of people with intellectual disability, and commitments to address these problems, have been clearly articulated in the National Disability Strategy⁵. Further priorities to address the mental health needs of people with intellectual disability were determined at the National Roundtable on the Mental Health of People with Intellectual Disability in 2013⁶, and in progressive documents such as the NSW Mental Health Commission's ten-year strategic plan⁷ and the Fifth National Mental Health and Suicide Prevention Plan⁸.

Australian intellectual disability mental health policy and services fall short of obligations under the [United Nations Convention on the Rights of Persons with Disabilities](#), and lag behind leading international standards⁹. This affects the way that services support this group and means that people with intellectual disability and mental ill-health often receive limited or inappropriate mental health care. Access to treatment is poor and highly variable, and illnesses are often misdiagnosed, unrecognised, and poorly managed. A number of barriers and enablers have been identified across all aspects of both the mental health and disability sectors. These range from systemic and organisational barriers, to a lack of services and poor-quality services related to deficits in knowledge³.

NHMRC Partnership Project

The National Health and Medical Research Council (NHMRC) funded Partnerships for Better Health Project "Improving the mental health outcomes of people with intellectual disability" (APP 1056128) brings together leading academics and representatives from health, disability, advocacy, education and supporting sectors to improve access to mental health services and quality of mental health services for people with intellectual disability (see [Appendix 2](#) for a list of all investigators and partners). The project uses large scale data linkage, comprehensive policy analysis and qualitative methodologies to establish an evidence base from which to guide the development of targeted, appropriate services for people with intellectual disability. The project is inclusive and a consumer representative group oversees and provides research and dissemination advice for the life of the project. The focus of this body of work is on prevention and equipping of the services sector to respond to the needs of people with intellectual disability. Findings underscore the need for cross-sector action, in partnership with people with intellectual disability and their carers to identify and deliver means of improving access to mental health services and supports. A summary of the key findings was presented at the Roundtable.

¹ Australian Institute of Health and Welfare. Disability Prevalence and Trends Canberra: AIHW; 2003.

² Cooper, SA et al. Mental ill-health in adults with intellectual disabilities: prevalence and associated factors. *The British Journal of Psychiatry*, 2007, 190(1): 27-35.

³ Whittle, EL et al. Barriers and Enablers to Accessing Mental Health Services for People with Intellectual Disability: A Scoping Review. *Journal of Mental Health Research in Intellectual Disabilities*, 2018, 11(1), 69-102.

⁴ Fuller, CG & Sabatino DA. Diagnosis and treatment considerations with comorbid developmentally disabled populations. *Journal of Clinical Psychology*, 1998, 54(1): 1-10.

⁵ Council of Australian Governments. National Disability Strategy 2010-2020. Canberra: Commonwealth of Australia.

⁶ NSW Council for Intellectual Disability. National Roundtable on the Mental Health of People with Intellectual Disability - Communiqué, 2013.

⁷ NSW Mental Health Commission. Living Well: A Strategic Plan for Mental Health in NSW. Sydney, NSW Mental Health Commission, 2014.

⁸ Department of Health. The Fifth National Mental Health and Suicide Prevention Plan. Canberra: Commonwealth of Australia, 2017.

⁹ Evans, E et al. Service development for intellectual disability mental health: a human rights approach. *Journal of Intellectual Disability Research*, 2012, 56(11), 1098-1109.

Eight Elements of an Effective System

At the 2013 National Roundtable on the Mental Health of People with Intellectual Disability, participants considered and supported eight key Elements of an effective system of mental health care for people with intellectual disability. They were asked to develop a set of priorities for action for each Element. The resulting [Communiqué](#) and subsequent [audit report](#), and the pre-roundtable survey for the 2018 Roundtable, are structured around these Elements of an effective system.

NATIONAL ROUNDTABLE 2018

Roundtable Methodology

Preparation for the 2018 National Roundtable involved a number of steps. Consultation with investigators and partners enabled the development of key aims and objectives for the Roundtable. Pre-roundtable “roadshows” with relevant government agencies in all states and territories were conducted by Professor Trollor, to engage and set the scene for the Roundtable. This also assisted the identification of senior representatives from key agencies within the advocacy, disability, health, criminal justice and education sectors to be invited as attendees. A pre-survey was developed and disseminated to prospective attendees to identify progress, barriers and enablers in agency and sector work in intellectual disability mental health. The survey informed the Roundtable background paper which summarised the pre-survey data and communicated important background information. The key barriers to delivering quality mental health care, as well as key enabling factors are summarised in [Appendix 2](#). The development of an innovative and engaging format for the Roundtable was a key priority. This included the identification and testing of appropriate software and hardware for live collation of the perspectives of Roundtable participants, including electronic voting on priorities for action.

The Event

The event was co-chaired by Ms Alanna Julian from the Council for Intellectual Disability and Professor Julian Trollor from UNSW Sydney. The event took place at Leighton Hall, The John Niland Scientia Building, UNSW Sydney. Following the Welcome to Country by Auntie Maxine Ryan, the day was officially opened by the Hon. Brad Hazzard, Minister for Health and Minister for Medical Research. Following contextualisation by experts, the latest evidence of the gap in mental health care for people with intellectual disability was explored. Subsequently, participants were engaged in brainstorming new potential priorities for action under each Element to close this gap. Using innovative technology, these priorities were ranked by attendees using a live mobile voting system. Subsequently, two table groups per Element worked to develop a set of SMART (specific, measurable, attainable, relevant, time-bound) Recommendations for the top 3 priorities within each of the eight Elements. A summation of the day was given at the conclusion of the event by Australia’s Disability Discrimination Commissioner, Mr Alastair McEwin.

Post Roundtable Consultation

Subsequent to the Roundtable, leads for each table had the opportunity to provide further information regarding the Recommendations arising from their work on their assigned Element. A draft version of the Recommendations was derived by integrating the outputs from each of the two working groups for each Element. This draft was circulated to table leads for final comments and approval.

ACKNOWLEDGEMENTS

The NHMRC Partnerships for better health team would like to thank the following people:

- All participants of the National Roundtable for their input and contribution towards a better mental health system for people with intellectual disability.
- Table leads who assisted on and beyond the day in collating and refining detailed Recommendations.
- Alanna Julian for co-chairing the National Roundtable.
- Auntie Maxine Ryan for her warm Welcome to Country.
- The presenters including Michael Sullivan, Alastair McEwin, Eileen Baldry, Helen Christensen, Jim Simpson, Jann Hayman, Karen Fisher, Leanne Dowse, Leanne Johnson and Rebecca Koncz.
- Australia's Disability Discrimination Commissioner Alastair McEwin for his excellent summation of the day.
- The Council for Intellectual Disability, in particular Jim Simpson for assistance in preparing the National Roundtable and the Communiqué.
- Aine Healy for assistance in promoting the event on social media.
- Lisa Clarke from the Council for Intellectual Disability for photography.
- The Agency for Clinical Innovation (ACI) for funding the catering.
- Thea Kremser for assistance with analysing the pre-survey, and with the National Roundtable preparations and the Communiqué.
- Rachel Roth for her administrative assistance throughout the whole process.
- Team 3DN for their assistance with various tasks during the event.

APPENDIX 1

Detailed Recommendations from SMART groups

The SMART Recommendations developed at the Roundtable are outlined on the following pages. They represent consensus on priorities for specific and appropriate action in key areas.



Element 1: **INCLUSION**

The mental health needs of people with intellectual disability are specifically considered and accommodated in all mental health initiatives.

Recommendation 1: Implement a co-design approach to planning, services and evaluation

A National Guide to Co-design would enable the development of mental health services that are responsive to people with intellectual disability. Its development and implementation should be led or supported by key national bodies such as the National Mental Health Commission, the Mental Health Stakeholder Group to the Australian Government Department of Health, and the Mental Health Principal Committee (MHPC) of COAG. The guide should be developed with people with intellectual disability, family members, advocates, and intellectual disability mental health professionals.

Recommendations for governance and review of the co-design approach must be established. High level support for the development and monitoring of a national co-design approach is necessary. The scope of work should either encompass whole of health with a strong mental health focus, or mental health alone.

The current work by the National Mental Health Commission on consumer and carer engagement and participation, and the NSW Mental Health Commission's work on developing co-design guide are potential templates or background for the national intellectual disability mental health co-design guide.

Suggested pathways

1. Initiate discussions on the development of a national guide to intellectual disability mental health co-design with the Department of Health, to develop a project plan
2. Identify and engage key stakeholders
3. Commission a National Guide to intellectual disability mental health co-design through lead national agencies
4. Seek high level endorsement, with targets determined by the scope of the guide. This could include endorsement from relevant state and national leads, or the MHPC of COAG.

Potential timeline

Suggestions 1–4 complete by 2020, with a report on progress and outcomes being determined by emerging governance and reporting framework.



Element 1: INCLUSION

Continued...

Recommendation 2:
All state/territory mental health plans should address inclusion of people with intellectual disability

Specific inclusion of people with intellectual disability in state/territory mental health plans is necessary to ensure their distinct mental health needs are acknowledged and met. Where this has occurred to date, the inclusion of action items on intellectual disability mental health has been a driver for key initiatives and enhancements. All state/territory plans should therefore include a section on intellectual disability, and/or have specific references and actions throughout the plan.

Suggested pathways

1. Raise the issue of inclusion of people with intellectual disability in state plans with the Mental Health Principal Committee of Australian Health Ministers Advisory Council (AHMAC)
2. Seek inclusion of an agenda item on the Council of Australian Governments Disability Reform Council
3. Raise the issue of inclusion of people with intellectual disability in state plans with peak bodies and advocacy groups
4. Initiate advocacy through agencies to mobilise sufficient ministerial and political support for this issue
5. Raise the issue of inclusion of people with intellectual disability in state plans with all mental health commissions through the joint Mental Health Commissions meeting to the end goal of developing a plan to incorporate intellectual disability in all future strategic plans and work plans of the various state and national commissions
6. Provide input into draft plans as needed.

Potential timeline

Suggestions 1–5 by the end of 2019; suggestion 6 as per revision of state plans.



Element 1: **INCLUSION**

Continued...

Recommendation 3: Establish appropriate support and funding models for primary care

The primary health sector currently struggles to respond adequately to the needs of people with intellectual disability and mental health problems. Factors contributing to the shortfall in primary care provision to people with intellectual disability and mental health needs are manifold, and arise through a combination of policy, services and provider factors. This Recommendation included several steps to improve the ability of the primary care system and primary care providers to meet the needs of people with intellectual disability and mental health needs.

Development and incremental refining of models of care would lead to improvements in care. PHNs could lead enhancement of capacity and skills in primary care. MBS items could be revised to recognise the complexity of diagnosis and treatment, and the time health professionals need to spend with a person with intellectual disability and other informants; the current MBS review may provide scope to address this issue. With appropriate resourcing, the Health Care Homes model also has substantial potential for people with intellectual disability.

Suggested pathways

1. Deliver submissions to the current MBS review that seeks representation of the needs of people with intellectual disability. This could be led by the National Mental Health Commission and others.
2. Seek a joint planning and commissioning approach for people with intellectual disability and mental health needs. The mental health needs of people with intellectual disability should be raised with the Department of Health through the Primary Health Network Advisory Panel on Mental Health, for consideration in the 5-year Horizon document that is currently under development. Senior representatives from the National Mental Health Commission and Mental Health Australia have a leadership role in this context.
3. People with intellectual disability and mental health issues should be included in the Health Care Homes trials. Whilst there are several competing priorities for the Health Care Homes trials, the complexity of health-related needs experienced by people with intellectual disability makes this group one of particular importance. Formal representation should be made to the Department of Health to this end.
4. Use the research findings presented at the Roundtable relating to primary care data to inform submissions for MBS item reform.

Potential timeline

Suggestions 1–4 initiated by the end of 2018.



Element 2: PREVENTION AND TIMELY INTERVENTION

People with intellectual disability and their families receive education and support to prevent, and to obtain early and timely assistance, for mental illness.

Recommendation 1: **Implement competencies in intellectual disability mental health in health, disability, justice and education sectors nationally**

Competencies in intellectual disability mental health describe core attributes of professionals, and provide roadmaps and tools for professional development in this field. Lack of skills and confidence has been repeatedly demonstrated in key professional groups and contributes to an inability to meet the mental health needs of people with intellectual disability. Competencies should be developed and implemented for each of the above sectors by adapting existing [competency frameworks](#) and [toolkits](#) such as those produced by 3DN, UNSW Sydney, or those in development for both disability and health professionals in Western Australia. An enabler is that 3DN's Competency Framework maps onto 3DN's IDMH e-learning which currently targets health professionals, disability professionals, and carers.

Suggested pathways

1. Building on existing work, seek support from the Mental Health Principal Committee of Australian Health Ministers Advisory Council (AHMAC) for uniform development and implementation of competencies in intellectual disability mental health for mental health services, including forensic services, nationally
2. Develop strategy with NDIS for the development of competencies in intellectual disability mental health for the disability sector nationally
3. Develop a strategy for the development of competencies in intellectual disability mental health for the education sector nationally.

Potential timeline

Suggestion 1 by the end of 2019; suggestion 2 by the end of 2020; suggestion 3 by the end of 2021.



Element 2: PREVENTION AND TIMELY INTERVENTION

Continued...

Recommendation 2: Provide health promotion and information on early signs of mental ill-health to young people with intellectual disability

Presently, people with intellectual disability are not specifically included in health promotion. Information on early signs of mental ill-health and what to do about them is not readily accessible to people with intellectual disability. To achieve improved inclusion in health promotion and awareness in this area, a broad-based strategy is required, underpinned by inclusive design. People with intellectual disability should be specifically included in health promotion initiatives, and accessible information about early signs should be developed for people with intellectual disability in order to support this group to improve their mental health. Roundtable participants recommended that this work is undertaken in partnership between consumers, advocates, disability and health service providers, and academic leads. Use of internet and social media platforms has gained traction in the general population. The potential of this medium should also be explored for people with intellectual disability.

Suggested pathways

1. Measure the current level of knowledge and attitudes about mental health in people with intellectual disability, and the current level of engagement with the internet and social media platforms
2. Scope evidence and review evidence-based models of improving health literacy
3. Approach the Department of Health to request inclusion of the needs of people with intellectual disability in all aspects of health promotion and prevention
4. In partnership with people with intellectual disability, co-design tools and information that are accessible to people with intellectual disability, and increase promotion in mainstream health channels.

Potential timeline

Suggestions 1–3 by the end of 2019; suggestion 4 by the end of 2020.



Element 2: PREVENTION AND TIMELY INTERVENTION

Continued...

Recommendation 3: Develop scalable, evidence-based tools to support health professionals to deliver effective mental health care for people with intellectual disability

Clinicians lack awareness of available evidence-based tools to assist assessment and management of people with intellectual disability and mental illness and related disorders. Whilst many tools and links to resources have been developed, these need organisation and coordinated promotion. A web-based portal is required to disseminate information to enable professionals to deliver more effective mental health care to people with intellectual disability. A clearing house model catering to key professional groups (general practitioners, developmental paediatricians, psychiatrists, mental health nurses, registered psychologists, etc.) was identified as the preferred option for hosting and dissemination of material.

Suggested pathways

1. Seek funding for the development of a clearing house for intellectual disability mental health resources
2. Liaise with relevant colleges and professional bodies to establish needs and mechanisms for uptake of materials, and for the embedding of resources in continuing professional development programs
3. Establish an online clearing house
4. Embed training materials in CPD programs of all relevant professional bodies.

Potential timeline

Suggestions 1-2 by the end of 2019; suggestion 3 by the end of 2020; suggestion 4 by the end of 2021.



Element 3: ACCESS TO SKILLED SERVICES

All mental health services provide equitable access and appropriately skilled treatment to people with intellectual disability.

Recommendation 1: Add positions in LHD mental health services to build capacity and workforce skills in intellectual disability mental health

People with intellectual disability are frequent users of mental health services but available evidence indicates poorly coordinated and inefficient care. Recently established clinical positions (including coordinator or clinical nurse consultant) have been pivotal in building workforce capacity and improving practice in intellectual disability mental health within LHD mental health services. Positions should be implemented in a coordinated manner at a whole of state level in each jurisdiction. The funding and establishment of such positions could be sought through either a coordinated state/territory budget enhancement, or as an initiative of an individual LHD. Coordinated implementation (embracing principles of co-design), core performance indicators, and strong evaluation of these positions was recommended.


Suggested pathways

1. State and territory leads to partner with national advocacy leads to determine strategy for development of this approach in each jurisdiction
2. State and territory leads to seek support within corresponding health departments for funding to support the establishment of intellectual disability mental health clinical coordinator type positions and their evaluation
3. Using co-design principles, evaluate the impact and outcomes of positions.

Potential timeline

Suggestions 1-2 by the end of 2019; suggestion 3 by the end of 2021.

Recommendation 2: Improve uptake and implementation of competency-based frameworks

Element 3 work groups acknowledged the value of competency-based frameworks to improve clinical practice in intellectual disability mental health. This Recommendation was covered under  [Element 2, Recommendation 1.](#)



Element 3: ACCESS TO SKILLED SERVICES

Continued...

Recommendation 3: Develop and implement minimum mandated intellectual disability health content in curriculum of relevant disciplines

Exposure to people with intellectual disability and their health needs during training will improve professionals' attitudes and capacity to address the mental health needs of this group. A striking deficit in this area is apparent in medical, nursing and psychology training, and should be addressed by adopting a co-production approach to the development of minimum mandated intellectual disability health content in each discipline. Extensive intellectual disability mental health content should be a core part of this material.

Suggested pathways

1. Determine target disciplines, establish a working group, and identify champions in each key discipline by the end of 2018
2. Approach Dean's governing bodies for discipline-specific support by mid-2019
3. Secure funding for curriculum projects, either individually or as a collective
4. Develop curriculum toolkits in key disciplines with minimum specified content
5. Trial curriculum toolkits across each of the core disciplines
6. Refine curriculum toolkits and seek national roll out.

Potential timeline

Suggestions 1-2 by mid-2019; suggestions 3-5 by the end of 2020; suggestion 6 by the end of 2021.



Element 4: **SPECIALIST SERVICES SUPPORT MAINSTREAM MENTAL HEALTH SERVICES**

A national network of specialist intellectual disability mental health professionals is available to support mainstream mental health services – by provision of consultancy and training, and through research.

Recommendation 1: Develop and implement a mental health policy framework for people with intellectual disability

The development and implementation of a national mental health policy framework was the lead Recommendation for Element 4. As featured at the Roundtable, reliable inclusion of people with intellectual disability in national and state mental health policy is lacking. Urgent work is required to develop and implement a national mental health policy framework. This will ensure meaningful inclusion of people with intellectual disability within all state and national mental health policies.

Suggested pathways

1. Identify state/territory and national mechanisms by which this issue could be raised
2. Seek high level support from Ministers and departmental leads at state and national levels
3. Brief the Mental Health Principal Committee on this and other relevant issues
4. Develop a framework for policy inclusion and seek high level sector endorsement.

Potential timeline

Suggestion 1 by the end of 2018; suggestions 2–4 by the end of 2019.



Element 4: SPECIALIST SERVICES SUPPORT MAINSTREAM MENTAL HEALTH SERVICES

Continued...

Recommendation 2: Better support and coordination for people with intellectual disability at mental health triage and intake

Access to mental health services for people with intellectual disability should be improved by ensuring that each component of mental health services has a defined clinical pathway and capacity to respond to the needs of people with intellectual disability. Arguably the greatest need is within entry points to mental health services. The development of robust clinical pathways will require mapping of the clinical journey for a person with intellectual disability, awareness of clinical resources and supports, and the implementation of reasonable adjustments. A number of issues arise including:

- the importance of implementation of adjustments to practice at every stage of the health care journey, to allow the mental health needs of a person with intellectual disability to be met
- the value of having well defined clinical pathways for people with intellectual disability developed in each core component of mental health services
- the importance of mapping and documenting available services and supports across all elements of health and disability, at a local, regional and state level.

Suggested pathways

1. Linking clinical pathway components to a database of resources for clinicians at each phase of the clinical journey, including triage and intake
2. The funding, development, and trial of a clinical pathways toolkit to enable services to map clinical pathways for each core component of their mental health service, which can ultimately be widely adopted
3. The funding, development, and trial of a service mapping tool to enable services to map available services and supports across all Elements of health and disability, at a local, regional and state level.

Potential timeline

Suggestions 1–3 by the end of 2020.



Element 4: SPECIALIST SERVICES SUPPORT MAINSTREAM MENTAL HEALTH SERVICES

Continued...

Recommendation 3: Ensure access to a specialist multidisciplinary team

Specialist multidisciplinary health teams are required for some people with intellectual disability because of their more complex mental health needs. The establishment and embedding of specialist multidisciplinary teams was viewed as highly desirable by the working groups. Specialist multidisciplinary health teams for people with intellectual disability provide higher level care and consultation for people with more complex needs. Multidisciplinary teams can either have a whole of health focus (including mental health) or a specific mental health focus. Each state and territory is at a different phase of development of such services. Leadership at a national, state and territory level is required to ensure uniform access to multidisciplinary teams for people with intellectual disability and mental health needs. State and territory working groups, which include support for representation by consumers, carers and advocates, are necessary for the development of models and business cases for funding enhancements and should be instituted in each state and territory.

Suggested pathways

1. Following principles of co-design and in partnership with intellectual disability health leads in academia, government, services, and advocacy:
 - a. Perform a national gap analysis
 - b. Review and scope preferred model of care
2. Develop health economic modelling to support state-wide networks of multidisciplinary health care across all ages
3. Seek state-based funding enhancements to support the development of multidisciplinary specialist teams in each state and territory.

Potential timeline

Suggestions 1a and 1b by the end of 2020; suggestions 2 and 3 by the end of 2021.



Element 5: COLLABORATION

Ongoing joint planning by disability services, schools and mental health and other relevant services including (a) identification of referral and treatment pathways, and (b) a framework and capacity for collaborative responses where intellectual disability and mental health needs co-exist.

Recommendation 1: Develop interdisciplinary practice in NDIS pre- planning and planning processes

Interdisciplinary practice in the pre-planning and planning of NDIS applications and supports is critical to ensuring cohesive supports for a person with intellectual disability. Interdisciplinary practice, particularly that which engages health or mental health professionals, has been limited by historical 'silos' between services. However, exemplars of good practice can be seen within highly specialised health and disability services, which offer either a multi- or interdisciplinary approach. Interdisciplinary practice is particularly important for people with complex support needs, including those with intellectual disability and co-occurring mental illness or challenging behaviour. Interdisciplinary practice frameworks and support must be developed to support interdisciplinary approaches by practitioners in the pre-planning and planning for NDIS participants. A key opportunity to get this right is within the NDIA's complex needs pathway that is currently under development.

Suggested pathways

1. Within the current pilot for people with complex needs the NDIS should develop a systematic process of interdisciplinary input including:
 - a. Guidelines for practitioner input to pre-planning, including format and content template
 - b. Guidelines for collation, evaluation and integration of advice from subject matter experts and external stakeholders
 - c. Formal provisions for involving practitioners in planning meetings and processes, including via email, telephone, and videoconferencing
 - d. Routinely providing feedback on outcomes of the planning process
2. Develop mechanisms to routinely identify and support participants with intellectual disability and mental health needs
3. Use identification to trigger and support interdisciplinary input into the planning process
4. Planners to seek interdisciplinary sources of information before the planning meeting
5. Ensure support for the NDIS participant with intellectual disability and mental health needs by:
 - a. Automatically allocating an NDIS specialist support coordinator for pre-planning
 - b. Supporting participant choice regarding who should provide information for NDIS planning; ensuring that interdisciplinary input is sought where appropriate
 - c. Identifying a mechanism for NDIS or participant to seek new or additional assessments or reports if needed to inform planning.

Potential timeline

Suggestion 1 by the end of 2018; suggestions 2–5 by the end of 2019.



Element 5: COLLABORATION

Continued...

Recommendation 2: Build capacity and resources for interagency collaboration

Resources are required to enhance interagency collaboration. This is particularly important as in many jurisdictions connectivity between agencies has been challenged by the implementation of the NDIS. Interagency collaboration benefits people with intellectual disability, professionals and services. However, there are currently limited resources to support and grow these collaborations. Lack of leadership due to devolution of state-based disability services risks regression of capacity in this area. Leadership is required in key agencies including NDIS, lead disability service providers, LHDs, PHNs, education, community services, and corrections to drive interagency resource development and implementation.

Suggested pathways

1. Lead commonwealth, state and territory agencies to consider development of an overarching collaborative charter for supporting people with intellectual disability and mental health needs
2. At a local level (e.g. NDIS, lead disability service providers, local health networks, PHNs, education, community services, corrections), ensure strong consumer and carer input by identifying and engaging locally relevant carer and consumer networks
3. At a local level, foster collaborative practice by forming joint working groups, communities of practice, and formal collaborative charters
4. Local leads to drive the development of resources. For example, consider services and interagency mapping, establish mechanisms for collaboration and resolution of disputes, establish shared training and education initiatives.

Potential timeline

Suggestions 1–4 by the end of 2019.



Element 5: COLLABORATION

Continued...

Recommendation 3: Through development of a co-design charter, ensure co-design of systems across levels of government, to support people with intellectual disability and mental health needs

Adoption of co-design approaches across government and other agencies will ensure consumer input into services and systems development, in a way that better meets the mental health needs of people with intellectual disability. The development of a co-design charter would be strengthened if led by key national leads such as the National Mental Health Commission, which has led the development of similar charters in the past. Key partners include people with intellectual disability and their families and advocates, the Department of Social Services, and the Department of Health.

Suggested pathways

1. Develop, through audit, a list of stakeholders nationally
2. Agree with stakeholders on a common understanding of, and framework for, co-design
 - a. Lead a consultation and development process
 - b. Develop draft charter; associated deliverables; accountability; reporting requirements and mechanism; implementation strategy
3. Agreed draft Charter and associated documents to be submitted to COAG
4. Through a COAG commitment to the Charter, seek formal sign up by all agencies at high level and agree to a set of deliverables, accountability, and reporting
5. Roll out to include strategy for raising awareness of obligations under Charter, and for building capacity and improving collaborative practice under the Charter.

Potential timeline

Suggestions 1–3 by the end of 2019; suggestions 4–5 by end of 2020.



Element 6: **WORKFORCE DEVELOPMENT AND SUPPORT**

Training in intellectual disability mental health to minimum standards for front-line and other professional staff in disability services, schools and health services, particularly including primary health and mental health services.

Recommendation 1: All education institutions to embed intellectual disability training, giving priority to health and mental health aspects

This Recommendation also links strategically to [📍 Element 3, Recommendation 3](#). Roundtable participants working on Element 6 suggested a broad strategy for implementation of this Recommendation involving a larger number of educational institutions.

Suggested Pathways

1. Identify key stakeholders: Universities, TAFE, private colleges, accrediting bodies, NDIS Quality and Safeguards Commission, peak consumer and carer groups
2. Determine priorities for audits and develop audit tools and methodology
3. Audit curriculum content in key priority sectors, disciplines and courses
4. Work with accrediting bodies or equivalent to gain support, agree to minimum content and set overall targets for inclusion
5. Develop and test 'minimum standards' curriculum toolkits for specific stakeholder groups
6. Advocate for local adoption of toolkit content to augment course content to meet standards.

Potential timeline

Suggestions 1–3 by the end of 2019; suggestions 4–6 by the end of 2021.



Element 6: **WORKFORCE DEVELOPMENT AND SUPPORT**

Continued...

Recommendation 2: Include mental health in National Standards for Disability Services

National standards relating to the provision of disability services (currently articulated in the National Standards for Disability Services) specify what is expected of disability services. Yet, the specific obligations for disability services in interaction with other support systems such as health, is lacking. The current and future standards should specifically outline health-related aspects in such a way that the responsibility of disability services in this area is clear, and in a manner that strengthens the interagency imperative between disability and health services.

Inclusion of health and mental health related aspects in the National Standards for Disability Services and future relevant standards documents will ensure that the responsibility of disability services in this area is clear.

Suggested pathways

1. Broaden approach to include both Health and Mental Health domains in the Standards
2. Lobby for inclusion of health aspects in National Standards for Disability Services when next reviewed, or in superseding documents
3. Evaluate existing Standards document for opportunities and leveraged e.g. around human rights and inclusion
4. Develop a working group with appropriate inclusive representation
5. Prepare and provide supportive evidence from Partnership Research to policy makers
6. Develop draft submission with suggested wording to cover both Health and Mental Health domains.

Potential timeline

Suggestions 1–5 by the end of 2019; suggestion 6 at next review of National Standards for Disability Services.



Element 6: **WORKFORCE DEVELOPMENT AND SUPPORT**

Continued...

Recommendation 3: Upskill the mental health workforce to a minimum standard

(See also:

 [Element 2,](#)
[Recommendation 1;](#)

 [Element 3,](#)
[Recommendations 1–3;](#)

 [Element 6,](#)
[Recommendation 1\)](#)

A broad range of professionals constitute the mental health workforce, with available evidence indicating a lack of skill and experience in intellectual disability mental health in multiple sectors and professional groups. Opportunities should therefore be sought to develop minimum workforce training across multiple groups. Professional bodies and specific service compartments need to be engaged in efforts and initiatives to address this Recommendation. Champions within each sector or professional group could link with existing expertise within specialised services to lead initiatives. Roundtable participants recognised the breadth of services and professional groups who provide mental health supports to people with intellectual disability, and this presents a challenge for this broad Recommendation.

Suggested pathways:

1. Identify key components of mental health workforce, from primary care, acute care, community mental health, and non-hospital specialists in relevant disciplines
2. Determine current knowledge and training needs in each component
3. Determine the potential for inclusion of minimum mandated content
4. Design tiered approach to training that progressively builds competencies; harnesses existing learning opportunities such as in-service education, grand rounds, and video resources that can promote reflective discussion
5. Develop marketing and promotion approach for available resources – e.g. competency frameworks, e-learning, existing specialist services and other resources
6. Collate and promote a national web-based clearing house of information about intellectual disability mental health for service providers, modelled on existing websites about defined mental health problems.

Potential timeline

Suggestions 1–5 dependent on sector or professional group but achievable within 24 months; suggestion 6 by the end of 2019.



Element 7: DATA

Collection and analysis of data which measures mental health needs, access to services, and outcomes of people with intellectual disability.

Recommendation 1: Create ongoing linkage between state and federal datasets to enable examination of mental health outcomes and service use for people with intellectual disability

Recommendation 2: Ensure NDIA & health/ mental health data exchange in order to aid planning and service improvement

Recommendations 1 and 2 for Element 7 are conceptually linked and have been presented as a united series of actions.

Historical and current linkage projects in this area highlight the value of big data in understanding the health needs of, and informing service responses to, people with intellectual disability. Big Data has the potential to answer key questions regarding the mental health status, service use and outcomes of people with intellectual disability, and has the capacity to inform improvements in service provision. High level leadership through COAG and agreement between NDIA, Australian Department of Health, the Australian Institute of Health and Welfare (AIHW), and state and territory health counterparts will be required to ensure that appropriate data linkage capacity and interrogation of linked data is supported.

Suggested pathways

1. Seek in-principle agreement from the NDIA, Department of Health, AIHW, and state and territory health counterparts. It is likely that COAG agreement through the relevant group will be necessary to achieve this. Consider including the NDIS Quality and Safeguards Commission in this process
2. Agree to the scope and terms of reference for work. This will require a commitment to an ongoing linkage and the engagement of content and process experts as well as academics active in this field
3. Work through legislative, ethical and technical issues associated with data sharing/matching. Existing data linkage processes at a commonwealth and state level, and current research linkages provide guidance
4. Identify mechanism for linkage and for data to be made available for analysis
5. Analyse data according to priority; ensure data is used to examine outcomes, interrogate service gaps, examine marked development and opportunities, inform the development of improved models for care and evaluate participant pathways
6. Utilise analysis to inform service and policy planning across NDIA, commonwealth health, state and territory health. This should be a collaborative process, with a cross-agency perspective
7. Use experience of data process to inform potential future improvements to data sets and data capture.

Potential timeline

Suggestions 1–4 by the end of 2019; suggestions 5–7 by the end of 2021.



Element 7: DATA

Continued...

Recommendation 3: Map intellectual disability mental health services and their gaps nationally

Service mapping will assist the identification of gaps in intellectual disability health and mental health services. Documenting service models and their development may assist other jurisdictions to embark on services development in this area and may showcase exemplars of best practice. Methodological approaches with other populations in several states have demonstrated the feasibility of this approach. A dedicated project would be required to develop this map.

Suggested pathways

1. Using co-design principles, engage states and territories in this initiative
2. Establish resource that documents current available qualitative and quantitative data
3. Identify key research methodology for service mapping and key research questions to be addressed
4. Collect data from each state and territory in a uniform way, ensuring attention to specific groups for example, people with complex needs, CALD groups, LGBTIQ, Aboriginal and Torres Strait Islander people, and people in contact with the criminal justice system
5. Analyse data and identify key strengths, gaps and vulnerabilities in service provision
6. Report national snapshot and use data to lobby for funding enhancements in jurisdictions where necessary.

Potential timeline

Suggestions 1–3 by the end of 2019; suggestions 4–6 by the end of 2020.



Element 8: MULTIPLE DISADVANTAGE

All Elements include specific focus on contributors to multiple disadvantages including poverty, isolated lives, alcohol and other drugs misuse, Indigenous status, CALD backgrounds and contact with the criminal justice system.

Recommendation 1: Develop national minimum standard for universal services access for people with intellectual disability

A national minimum standard for access to health and human services for people with intellectual disability would overcome key barriers to accessing services. High level agreement with this approach would need to be canvassed.

This Recommendation seeks to develop and deliver a high level agreement on national minimum standards and could be sought specifically for people with intellectual disability, or more broadly for people with disability, with a strong emphasis on people with intellectual disability.

Suggested pathways

1. Determine through sector consultation, whether initiative should seek intellectual disability specific Standard, or broader disability Standard
2. Determine feasibility of the inclusion of this standard in revisions of the National Disability Strategy (for example, in principles, approaches or relevant components of outcomes)
3. Seek broad-based support for initiative, including financial support, by seeking state-based Ministers to champion. COAG support seen as essential for success
4. Formation of an advisory group inclusive of all stakeholders – e.g. consumers, family members, member groups of professionals, etc.
5. Determine a work plan including timeline for consultations, research, drafts for public comment, finalisation for Standards and implementation plan
6. Implementation phase with strong communication strategy, stakeholder and community engagement, and evaluation.

Potential timeline

Suggestions 1-2 by the end of 2019; suggestions 3-5 by mid-2021; suggestion 6 to take an additional 24-48 months.



Element 8: MULTIPLE DISADVANTAGE

Continued...

Recommendation 2: Establish national guidelines for cross- agency collaboration for people with intellectual disability and mental health needs

The goal of this Recommendation is the production and implementation of national guidelines for cross-agency collaboration at local, state and commonwealth levels. Cross-agency collaboration is key to ensuring cohesion of multiagency supports for people with intellectual disability, and is critical for people with multiple disadvantages.

Suggested pathways

1. Map relevant stakeholders in each state, and collate exemplars of cross-agency collaboration in Australia
2. Identify international best practice models, through field research – e.g. Churchill Fellowship
3. Determine capacity for individual agencies – e.g. NDIS, health, education, corrections, etc. to support cross-agency collaboration, seeking opportunities where appropriate (e.g. the NDIS Pathway for people with complex needs)
4. Determine feasibility of establishing cross-agency collaboration as a key approach incorporated within revisions of the National Disability Strategy
5. Produce national guidelines for cross-agency collaboration, and facilitate implementation at a local and state level in key agencies.

Potential timeline

Suggestions 1–4 by the end of 2019; suggestion 5 by the end of 2020.



Element 8: MULTIPLE DISADVANTAGE

Continued...

Recommendation 3: Disability, justice and mental health guidance within the NDIS

A greater understanding is required of the needs and factors that influence outcomes for people with intellectual disability who have contact with the justice system. Interagency collaboration is a concrete step likely to underpin quality service provision to people with intellectual disability who have contact with the justice system. An important initial step is to ensure that the NDIS pathway for people with complex needs has the capacity to cater to the needs of people who have contact with the justice system.

Suggested pathways

1. Assess NDIS complex needs pathway and ensure strong consideration of multiple disadvantage
2. Conduct scoping work to identify gaps and best practice within all relevant agencies and service providers
3. Review the NDIS legislation to enhance focus on people with multiple disadvantage, ensure availability of service providers delivering specific supports in this area
4. Undertake analysis of linked data to examine trajectories of those with multiple disadvantage to understand drivers and outcomes
5. Consult and develop potential proposals for capacity building projects in this area.

Potential timeline

Suggestion 1 by the end of 2018; suggestions 2–5 by the end of 2020.

APPENDIX 2

Attendee list

A list of attendees can be viewed [here](#).

Partnerships for Better Health Project

A detailed description of the National Health and Medical Research Council (NHMRC) funded Partnerships for Better Health Project “Improving the mental health outcomes of people with intellectual disability” (APP 1056128) can be viewed [here](#).

Pre-roundtable survey results summary

A summary of the barriers and enablers identified in the pre-survey can be found [here](#).

Roundtable program, speaker biographies and video highlights

The National Roundtable program and speaker biographies can be viewed [here](#).

Roundtable video excerpts can be viewed [here](#).

NOTES



UNSW
SYDNEY



DEPARTMENT OF
DEVELOPMENTAL
DISABILITY
NEUROPSYCHIATRY



Council for
Intellectual Disability



ACI NSW Agency
for Clinical
Innovation



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Applied Health
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Inclusion Australia
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