

Intellectual Disability Mental Health

What we've learned and the way
forward

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NSW Ministry of Health



Introductions

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Intellectual Disability Mental Health – Strategic focus

Accessible information about mental health services for people with an intellectual disability and their families and carers

Clinical service pathways for people with intellectual disability through mental health services

Supports to enhance strategic partnerships for people with intellectual disability and mental illness

Specialist capacity to meet the more complex needs of people with coexisting mental illness and intellectual disability.



Turning strategy into action

Easy-read mental health resources

Contributing to the evidence of what works through evaluation and research

Improved skills and confidence of mainstream mental health staff

Access to up-to-date education

Improved resources for families, carers and people with disability

IDMH NDIS Residual Functions Program

Locally based IDMH roles

Improved sub-specialty access

Improved pathways and relationships between ID Health teams and mental health services

Statewide IDMH Hubs, Project ECHO and Kids Webinar Series

Specialist Intellectual Disability Mental Health Services

▶ **Mental Health Reform – the “Hubs”**

- Statewide Intellectual Disability Mental Health Outreach Service (SIDMHOS) (Sydney LHD)
- SCHN Mental Health Intellectual Disability Hub

▶ **Department of Developmental Disability Neuropsychiatry, UNSW**

- Research
- Practical tools and resources
- Education and training

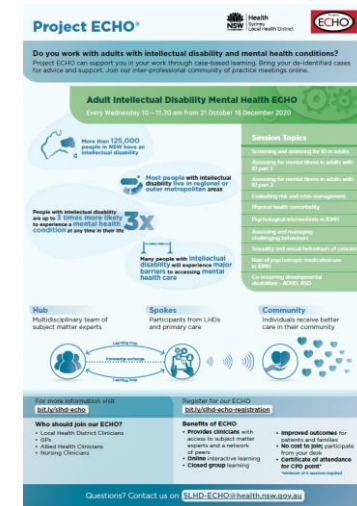
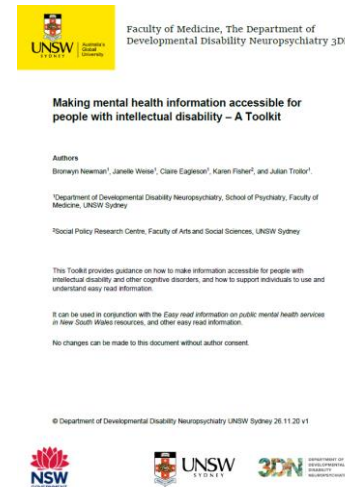
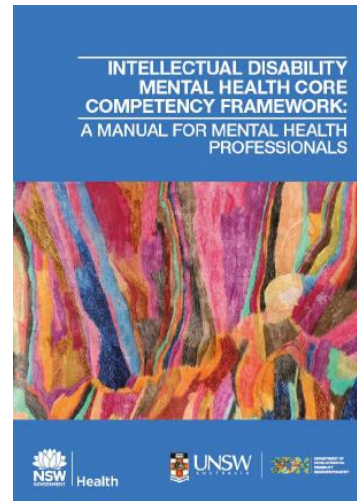
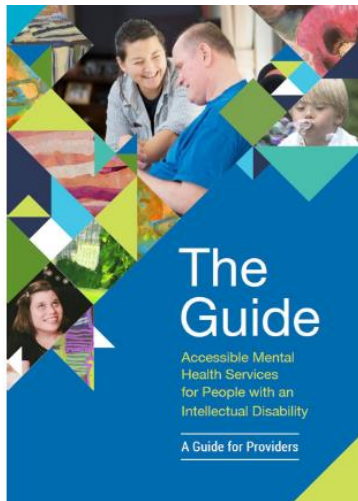


The IDMH NDIS Residual Functions Program

- ▶ Funded 2018-19 to 2020-2021 from the NSW Government
- ▶ Established time limited programs in ten local health districts and two specialty health networks and six IDMH positions in specialised intellectual disability health teams
- ▶ Programs had shared aims of
 - ▶ Increasing access to mental health services for people with intellectual disability
 - ▶ Improving skills, capacity and confidence of mainstream mental health staff to work with people with intellectual disability and co-occurring mental health problems
- ▶ Each program was led by the local health district or specialty health network to target:
 - ▶ Local population demographic
 - ▶ Specific mental health needs
 - ▶ Capacity, skill and experience of mainstream mental health staff
- ▶ Each of the twelve programs had a clinical and/or capacity building focus

Capacity Building

- ▶ In this context, capacity building refers to the program's aims to :
 - ▶ Build skills and confidence of staff
 - ▶ Provide access to increased training and support for staff
 - ▶ Connect with families, carers and people with intellectual disability
 - ▶ Improve the range of evidence based therapies available for staff to offer
 - ▶ Develop and embed resources to support ongoing care across mental health services
 - ▶ Develop pathways and relationships with other services including LHDs, NDIS providers, Primary Health Networks, private providers and disability services



The twelve services

LHD	Program	Description
Central Coast LHD	Disability Navigation, behavioural assessment and capacity building	<ul style="list-style-type: none"> Disability Navigator to work with people with ID and MH problems accessing services Paediatric behavioural triage clinic model with enhanced assessment capacity for children presenting with behavioural problems
Hunter New England LHD	MH-ID team	<ul style="list-style-type: none"> Clinical support and capacity building to ED, inpatient mental health and community mental health
Justice Health and Forensic Mental Health Network	IDMH in custodial settings	<ul style="list-style-type: none"> Support for people with ID, JHFMHN and custodial services to plan the release of people with IDMH in prisons.
Murrumbidgee LHD	IDMH clinic	<ul style="list-style-type: none"> Paediatric and adult IDMH psychiatry clinic and care coordination support Brokerage model to upskill supported independent living providers in accepting and caring for people with ID and MH conditions
Northern Sydney LHD	IDMH education	<ul style="list-style-type: none"> Development and establishment of comprehensive training package with 3DN
Sydney LHD	IDMH Social Worker	<ul style="list-style-type: none"> Establishment of a social work position to enhance existing SLHD IDMH service.
Sydney Children's Hospital Network	Transfer of Care team	<ul style="list-style-type: none"> Clinical and transition support for children and families with complex needs
South Eastern Sydney LHD	IDMH project	<ul style="list-style-type: none"> Shared project with SESLHD ID Health Team to enhance care pathways
South Western Sydney LHD	IDMH project	<ul style="list-style-type: none"> Focused work and education with LHD staff and NDIS providers to improve quality of care, services and coordination
Southern NSW LHD	IDMH clinic	<ul style="list-style-type: none"> IDMH clinic, care coordination support and collaboration with TAFE to increase educational opportunities
Western NSW LHD	IDMH clinic	<ul style="list-style-type: none"> IDMH psychiatry clinic
Western Sydney LHD	IDMH outreach team	<ul style="list-style-type: none"> IDMH CNCs to work with local health teams to provide specialist care for people in contact with mental health services

Common links and collaboration

- ▶ Each service included both clinical and capacity building elements
- ▶ Most services targeted adult care, with two services focusing on the needs of children and young people
- ▶ Most services accessed and promoted existing education resources including:
 - ▶ The IDMH Core Competency Framework
 - ▶ The Guide: Accessible Mental Health Services for People with Intellectual Disability
 - ▶ IDMH e-learning modules
- ▶ Strong relationships developed between IDMH leads and NDIS providers. This increased access to support for providers to facilitate care of consumers with more complex needs
- ▶ Collaboration was a key part of the program. IDMH leads from each LHD were interested to share ideas, resources and projects.

The role of evaluation

- ▶ The Social Policy Research Centre (SPRC) at the University of NSW is conducting evaluations on behalf of the Ministry on the:
 - ▶ Residuals Functions Program
 - ▶ IDMH Hubs
- ▶ Evaluations have / are providing valuable information about what is working and what could be improved
- ▶ Evaluations also provide important evidence about the effectiveness and worth of programs
- ▶ These evaluations are 'formative' which means the learnings can inform improvements whilst the evaluation is still underway



Lived Experience Researchers

- ▶ The evaluations were designed to ensure all voices are heard
- ▶ Co-design and lived experience participation are key features of the evaluation processes
- ▶ Lived Experience Researchers contribute to:
 - ▶ designing research processes
 - ▶ participating in data collection
 - ▶ conducting analysis
 - ▶ reviewing and providing advice on reports
- ▶ Lived Experience Researchers:
 - ▶ contribute to more relevant research processes
 - ▶ increase our engagement of consumers and carers
 - ▶ enhance our learning opportunities
 - ▶ make the end results more meaningful for all



Evaluation of the Residual Functions Program – what consumers and carers told us

Consumer and carers liked:

- ▶ Improved access to mental health services
- ▶ Feeling that the services offered through the program were relevant and welcoming to people with ID
- ▶ Improved support within residential settings
- ▶ Improved relationship with family
- ▶ Changed lives

Further suggestions for change

- ▶ Make existing mainstream mental health services more relevant and welcoming for people with ID
- ▶ Concerns about the short-term nature of the RFP – especially concerns about losing access to a specialised psychiatrist



Lessons Learned

- ▶ Statewide coordination meant that programs saw themselves as part of a bigger system, and were more engaged in supporting one another across traditional LHD boundaries
- ▶ Further consistency in the activities in each LHD will support better access by consumers and collaboration with NDIS
- ▶ Despite changes, much more needs to be done to support mainstream services to be more welcoming, respectful and accessible by people with intellectual and developmental disability
- ▶ Data systems do not yet adequately capture people with intellectual and developmental disability accessing NSW mental health care. Having and applying this data better helps local services to tailor their offering and see the need for enhanced services
- ▶ The importance of promotion, especially in non traditional ways



The future of IDMH in NSW

- ▶ Continued implementation of the Statewide IDMH Hubs
- ▶ Ongoing development of a statewide IDMH Network
- ▶ Work with inpatient and community mental health teams to continue building confidence and skills to meet the mental health needs of people with ID
- ▶ Promote whole of government coordination through systems where people with cognitive impairment are overrepresented
- ▶ Facilitate pathway development between existing and new service providers with focus on NDIS
- ▶ Address systemic barriers that limit access to mental health care for people with ID
- ▶ Consolidate the enhancements made and continue to build the system's capacity and responsiveness



Resources to support mental health care for people with intellectual disability

▶ Easy Read Mental Health Resources

20 information sheets for staff to share with people with low literacy about their mental health care in NSW, including information about introducing services, the Mental Health Act and how to make complaints:

<https://www.health.nsw.gov.au/mentalhealth/services/consumers/Pages/easy-read-mental-health-info.aspx>

▶ MySigns

A device based application to help families record mood and behaviour of people with limited verbal communication to share with health professionals: <https://www.mysigns.health/>

▶ Healthy Minds

An online easy read tool for people with intellectual disability to recognise and better regulate their thoughts and feelings: <https://www.blackdoginstitute.org.au/resources-support/digital-tools-apps/healthy-mind/>

▶ Positive Cardiometabolic Health for people with intellectual disability resources:

<https://www.3dn.unsw.edu.au/resources-people-lived-experience/people-intellectual-disability>

▶ ACI ID Network resources

Including social stories on different aspects of hospital care, Admission to discharge planners and communication tools:

<https://aci.health.nsw.gov.au/networks/intellectual-disability/resources>

Resources for staff

- ▶ **ID Health Data Portal:** A portal for staff to understand the demographics and health service usage of people with ID in their LHD: <https://idhealthdataportal.unsw.edu.au/>
- ▶ **IDMH e-learning resources:** 15 modules available on My Health Learning, covering assessment, treatment, recovery and managing challenging behaviour
- ▶ **Project ECHO IDMH Series:** A series of ten focused IDMH sessions that blend a short education session with a grand rounds- style clinical presentation and review. Hosted by SIDMHOS: <https://sydneyproject.healthpathways.org.au/ProjectECHO.aspx>
- ▶ **SCHN Kids Webinar Series:** Targeted webinars on adapting mental health care for kids with intellectual and developmental disability: <https://www.schn.health.nsw.gov.au/find-a-service/health-medical-services/mental-health-services/sch-chw-mhid>
- ▶ **The Guide: Accesible Mental Health services for People with Intellectual Disability:** <https://www.3dn.unsw.edu.au/the-guide>
- ▶ **IDMH Core Competency Framework:** <https://www.3dn.unsw.edu.au/IDMH-CORE-COMPETENCY-FRAMEWORK>
- ▶ **Responsible prescribing of psychotropic medications podcast:** <https://www.3dn.unsw.edu.au/education-resources/health-mental-health-professionals/positive-cardiometabolic-health-people-id/responsible-psychotropic-prescribing-people-intellectual-disability-podcasts>