Building accessible mental health services for people with an intellectual disability

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Main Points

• Determinants of health inequalities
• Evidence of health inequalities
• Improving access to mental health services
• Key components of accessible mental health services
• Responsibilities of services and practitioners
• Capacity building initiatives in ID mental health
• Coming soon to a LHD near you
• Local capacity building
• Questions
Key determinants of health inequalities

Individual → Environmental → Societal → Health inequalities
Evidence of mental health inequalities

• Prevalence of mental and physical disorders
• Poor access to mental health services
• Treatment outcomes & endpoints
• Confidence and competence of workforce
• Patterns of service use and access
Death rates and comparative mortality in people with ID in NSW

<table>
<thead>
<tr>
<th>Age specific death rate (per 1000 people)</th>
<th>5-69 age groups</th>
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<tbody>
<tr>
<td>ASMR ID</td>
<td>4.7</td>
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<tr>
<td>ASMR Non ID</td>
<td>1.8</td>
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<tr>
<td>CMF ID/Non ID</td>
<td>2.6</td>
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Leading underlying causes of death in people with an ID
Top 5 potentially avoidable deaths in people with an ID

Notes:
1. Potentially avoidable Deaths are:
   • Potentially preventable deaths are those amenable to screening and primary prevention, such as immunisation,
   • Deaths from potentially treatable conditions are those amenable to therapeutic interventions
2. Proportion of potentially avoidable deaths (over all deaths with known causes) in ID cohort is 46%, versus 22% in the Non ID cohort
Evidence of Mental Health Inequalities

- Prevalence of mental and physical disorders
- Poor access to mental health services
- Treatment outcomes & endpoints
- Confidence and competence of workforce
- Patterns of service use and access
Health and wellbeing of people with ID in the NSW service systems: data linkage

- High rates of admission
- Longer admissions
- Longer community mental health service visits
- Higher service costs
- Skewed diagnostic profiles
- Worse situation for people with ID not known to disability services
- Higher rates of ‘unknown’ diagnoses
- Poor diagnostic recognition of ID within mental health
Why is Access to Mental Health Services and Supports Difficult?
How Do We Improve Mental Health Supports?

Vision
• The highest attainable standard of mental health and wellbeing for people with an intellectual disability.

Mission
• To improve mental health practice and policy for people with an intellectual disability.

Guiding Principles
• Human rights
• Equity in mental health care
• Person-centred approach
• Promoting independence
• Recovery-oriented practice
• Evidence-based
• Innovation in health services
• Collaboration
Key Components of Accessible Mental Health Services

- Adaptation of Clinical approach
- Access to mental health services
- Access to specialised IDMH services
- Identification of care pathways
- Training for practitioners
- Interagency partnerships
- Data collection and evaluation
Adaptation of Clinical Approach

- Preparation and reasonable adjustments
- Effective communication
- Decision-making and mental health care
- Working with family and carers
Access to Mental Health Services

- A right to timely access to mental health services
- Initial mental health care needs met by mainstream, in primary care, and private and public mental health services
- Typical pathways through mental health services
- Coordination of mental health, health and disability supports through collaborative partnership between service providers
- Thorough assessment and adequate documentation
Access to specialised IDMH services

- Limited but these provide:
  - advice and a referral pathway for mainstream services;
  - review and second opinions in situations of complexity;
  - accessibility through the utilisation of e-medicine, such as Telemedicine, particularly in rural and remote areas.
  - time limited management
  - advice in developing strategies for service enhancement
    - educational programs
    - development of service models
    - interagency collaborative initiatives;
Identification and development of care pathways

• Care providers can improve access for people with an ID by:
  – identifying a clear clinical pathway
  – designating ID mental health clinical care coordinators
  – developing specific ID mental health teams
  – developing systems for coordinated transition
  – ensuring appropriate transfer and handover to other services
  – developing capacity in both disability and health systems for more complex areas: behaviours, forensic, multiple and complex disabilities
Training for practitioners

• Training and education initiatives in ID and mental health should be:
  – a core component of training in mental health and disability services
  – in undergraduate and postgraduate education in relevant disciplines (TAFE, medicine, nursing, psychology, allied health, specialist general practice and psychiatry training)
  – interdisciplinary and culturally inclusive
  – available in a flexible format,
  – available in a tiered manner
Interagency partnerships

• Best practice means active collaboration and will involve:
  – interagency collaboration and a multidisciplinary approach
  – sharing information
  – formal strategies to enhance cross-sector collaboration
  – considering families and carer(s) as partners and/or experts
  – joint assessment of people with an ID with other relevant agencies such disability services and education;
  – capacity for urgent referrals to mental health services from disability services, and vice versa;
  – capacity for co-management
  – joint education and training initiatives
Data collection and evaluation

• Currently there is no systematic collection and analysis of data
• Local MH Data:
  – the capacity of health services in ID mental health, including the accessibility of services, development of clinical pathways, training and education of staff and availability of specialist ID mental health services.
• State and national data:
  – Medicare Benefit Schedule data, Pharmaceutical Benefits Scheme data and State-based MHS data collections.
  – determine service use and mental health outcomes for people with an ID nationally
• Linkage to data collected under the National Disability Insurance Scheme.
Implications for Services

• Adaptation of existing services and models
• Developing collaborative and multidisciplinary approaches
• Providing training
• Introducing new systems
For All Mental Health Service Providers

• Responsibilities include:
  – Recognising people with an ID, including those with challenging behaviour, as core business
  – Provision of accessible mental health services to a person with an ID and their carer/s
  – Providing information for consumers and their families using easy-to-understand language or using augmentative and alternative communication where appropriate
  – Working in a collaborative and coordinated manner with other supports
  – Supporting return and maintenance of optimal functioning
  – Ensuring linkage to the client’s primary health care practitioner to facilitate continuity of care
  – Fostering the development of skills in ID mental health
For Disability Services

• Responsibilities include:
  – Recognition that many people with ID will require specific mental health supports
  – Determining and documenting local and regional pathways to accessible mental health services (GPs, specialists, ID health and mental health experts)
  – Working in a collaborative and coordinated manner with mental health supports
  – Considering joint capacity building with mental health services
  – Fostering the development of skills in ID mental health
Progress in IDMH Capacity Building

- State-wide survey of MH staff attitudes, confidence and learning needs in ID
- Training curriculum for mental health workers
- Competencies in IDMH for the NSW Mental Health
- Training strategy for psychiatry trainees
- Submissions to government on service and workforce
- Service model development in ID mental health
- National audits of ID health content in both Medical and Nursing curricula in universities across Australia; next step- a National ID Health toolkit
- National General Practice data on health and mental health, treatment, medicines use
- NSW mental health service use and costs
National Round Table in ID & Mental Health

Key elements of reform

Priorities for action

– Inclusion in all mental health initiatives
– Prevention and timely intervention
– Equitable access and skilled treatment
– Specialists in ID mental health
– Collaboration between agencies
– Workforce education and training
– Data collection and interrogation

Further National Developments in ID Mental Health

Now on NSW CID’s Website
Available free online
$15 per hard copy

3dn.unsw.edu.au

The Guide

- Specifies specific roles and responsibilities of the individual and the organisation
  - Primary health care
  - Public mental health
  - Private mental health
  - Specialist ID health
- At 2 levels:
  - Fundamental or basic roles and responsibilities
  - Further enhancement of practice and services
The Vision

Accessible mental health services for people with an intellectual disability.
Introduction

WHAT IS INTELLECTUAL DISABILITY?

Intellectual disability (abbreviated as ‘ID’ throughout this Guide) is the term used to describe permanent impairment of general mental abilities which has a significant impact on adaptive function. An ID is a lifelong disability which first becomes apparent during the developmental period, before the age of 18. An ID is diagnosed using a combination of results from standardised tests of intelligence and adaptive functioning.

On tests of intelligence, people with an ID generally perform about two standard deviations or more below the average for the population, which is an Intelligence Quotient (IQ) score of approximately 70 or below. Current diagnostic criteria emphasise measurement of adaptive functioning rather than reliance on IQ scores alone. Adaptive functioning describes how well an individual copes with everyday tasks, for example conceptual, social and practical skills. A more detailed definition can also be found in the Glossary at the end of this document.

At all stages of life, people with an ID are at least two to three times more likely to have a mental disorder than the general population.

The severity of ID can be mild, moderate, severe or profound. People with an ID are therefore a diverse group with highly varied support needs depending on their level of disability. Having an ID is associated with a high rate of co-occurring medical conditions and mental disorders. The mental health support needs of people with a mild ID can often be met within mainstream mental health services. However, people with communication defects, more severe ID, and comorbid health problems often require a more specialised approach to mental health care.

The focus of the Guide is people with an ID, rather than the broader group of people with developmental disability. Developmental disability refers to permanent mental or physical impairment arising in the developmental period. While many people with developmental disability have an ID, some do not. For example, someone may have cerebral palsy or autistic disorder with no intellectual impairment.

MENTAL HEALTH IN PEOPLE WITH AN INTELLECTUAL DISABILITY

At all stages of life, people with an ID are at least two to three times more likely to have a mental disorder than the general population.

Despite this, many people with an ID experience major barriers when trying to access mental health services. The development of accessible mental health services for people with an ID in Australia lags behind internationally accepted practice. The experience of family, carers and consumers is that mainstream mental health services do not readily accommodate the needs of people with an ID. Workforce capacity in this area is lacking, and mental health professionals have limited training, education and expertise in ID mental health. While preventative mental health programs are broadly aimed at all Australians, programs that specifically assist people with an ID are largely non-existent.

Specialist ID mental health services are uncommon and are limited to a few highly specialised professionals and centres. Service models and pathways of care for people with an ID and mental disorders are generally unclear.

Data on mental health service use or mental health outcomes for people with an ID is not systematically collected. Key national mental health policy documents recognise the needs of people with disabilities, including those with an ID. However, the implementation of mental health policy does not uniformly address the needs of people with an ID.

People with an ID represent a diverse population with diverse needs. The development and provision of accessible mental health services for people with an ID requires deliberate and sustained action from individuals, services and policy makers. This Guide highlights opportunities for action at each level of the mental health service system in order to meet the fundamental right of people with an ID to access free or affordable mental health care.
Background

THE RELATIONSHIP BETWEEN INTELLECTUAL DISABILITY AND MENTAL HEALTH

People with an ID experience very poor mental health compared to the general population, with common mental disorders occurring around two to three times more frequently. This predisposition to mental ill-health is apparent across the lifespan, including in children, young people and adults. At any one time, an estimated 20–40% of people with an ID will be experiencing a mental disorder of some kind. Simple examples of this vulnerability include the over-representation of schizophrenia by two to four times, and its earlier onset in people with an ID compared to the general population. In addition, higher rates of dementia are apparent in older persons with an ID compared to the general population.

Vulnerability to mental disorders in people with an ID is underpinned by a variety of biological, psychological, and social factors. Specific genetic conditions associated with ID can increase the risk of psychopathology and can develop early brain abnormalities and pharmacological treatments and their side effects. People with an ID are also at increased risk of a range of physical health conditions which may increase the risk of mental ill-health.

The presence of an ID usually affects a person’s coping skills and autonomy, creating greater susceptibility to stress, and thereby increasing psychological vulnerability. Further risk arises from the reduced opportunities to engage in a range of life choices, and restricted social networks that people with an ID often experience.

Other social factors which impact mental health include poverty, a higher likelihood of contact with the criminal justice system, negative experiences during schooling, and financial and emotional strain within the family. Furthermore, people with an ID experience higher rates of physical and sexual abuse which can further magnify their vulnerability to mental ill-health.

THE PRESENTATION OF MENTAL DISORDERS IN PEOPLE WITH AN INTELLECTUAL DISABILITY

The presentation of both physical and mental health problems can be influenced by a person’s level of ID and the presence of any associated communication difficulties. People with milder ID and good communication skills are usually able to describe what they are experiencing, and typically present in a manner familiar to most mental health professionals.

However, presentation is often atypical in those with more severe ID or in people with communication difficulties. This can mean that mental disorders mainly present as problematic behaviours. Therefore, individuals showing behavioural changes require careful assessment for a range of potential contributing factors including underlying mental or physical health conditions. Such complex presentations highlight the importance of a multidisciplinary approach to assessing behavioural difficulties in people with an ID.

It is critical for those working within the mental health profession to understand the phenomenon of ‘diagnostic overshadowing’. Diagnostic overshadowing means that symptoms of mental illness are misattributed to the ID rather than being recognised as part of the manifestation of a mental disorder. Mental health professionals should familiarise themselves with assessment and management of mental disorders in people with an ID by seeking specific training opportunities and resources (see Appendix 7 – Training and Education p. 67).

“Comprehensive assessment is central to making an accurate diagnosis and treatment.”

– Psychologist, ID mental health service
Guiding Principles

Mental health services for people with an ID must be underpinned by a human rights framework which promotes the inclusion and independence of people with an ID. Mental health service provision should be grounded in a person-centred approach and adopt recovery-oriented practices.

Furthermore, the Mental Health Statement of Rights and Responsibilities states that Australian governments have a responsibility to support the ongoing development of a range of timely, high-quality, recovery-oriented, and evidence-based services. These should be built around both community-based and specialist social support, and integrated with mental health, general health, and disability services. These principles are outlined below.

RIGHTS

A human rights framework in health care identifies people with a disability as having a right to health and health care. In relation to health services, the United Nations Convention on the Rights of Persons with Disabilities (CRPD) requires persons with disabilities to have access to the right to health and the highest attainable standard of health without discrimination. In a mental health context for people with an ID, this means ensuring:

- the same range and quality of free or affordable mental health care available to those without an ID;
- mental health services which address mental health conditions arising concurrently with ID, and services which assist in preventing secondary disabilities.

accessible mental health services which are provided as close as possible to the person's own community, including in rural and remote areas;

mental health professionals who provide a high quality of mental health care and uphold ethical principles; and

a system which prevents discriminatory denial of mental health care and promotes high standards of mental health care.

Mental health consumers with reduced capacity, including those with an ID, should be supported to understand and exercise their rights.

PERSON-CENTRED APPROACH

A person-centred approach to mental health maximises the involvement of the person with an ID in decision-making, rather than viewing them as passive recipients of care.

In a person-centred approach, the individual is central to their care plan and to any decisions made with respect to their mental health. The person-centred approach seeks to understand the situation from the person's own perspective, discovering what is important to them, taking into account their age, community and culture.

The person with an ID should be provided with choices about their mental health care, in keeping with their own capacity and age. While the person is the focus, family and carers should be consulted where appropriate. Service providers in both health and disability networks can be viewed as partners in this approach, working together to provide a cohesive system of person-centred mental health support.

INCLUSION

People with an ID have the right to full participation in all aspects of community life. People with an ID have the right to access all components of mental health services, including mainstream and specialised mental health services. They should not be refused access to a service due to the presence of an ID. This extends to access to population health programs aimed at the prevention of mental disorders. To achieve this, some people with an ID will require support and the provision of accessible materials about mental health. To ensure inclusion, mental health services and providers may need to significantly adjust their approach, including addressing issues of the preparedness of services and staff. This includes their willingness to engage and actively include family members and support staff in planning, implementation, and review of treatment programmes.

Mental health services need to promote and facilitate an inclusive approach towards people with an ID and act in a way that is guided by positive and non-discriminatory beliefs and attitudes.

"The person is the expert of their own experience."

- Mental health professional, disability service

PROMOTING INDEPENDENCE

Mental health care for people with an ID should recognise the autonomy of individuals with an ID whilst acknowledging their age and capacity, and work in a manner that maximises independence.

Given the differing capacities of individuals with an ID, mental health services must ensure that
Key Components of Accessible Mental Health Services

Incorporating the following major elements into clinical practice will substantially improve accessibility and the quality of mental health care for people with an ID.

ADAPTATION OF CLINICAL APPROACH

In order to best meet the mental health needs of a person with an ID, mental health professionals must adapt their clinical approach. The key adaptations, which will assist the tailoring of mental health consultations are described below. More information can be found in the Implications for Mental Health Services section, p. 26.

Preparation and Reasonable Adjustments

Preparing for a consultation with a person with an ID may involve making the following adjustments:

- simplifying appointment and referral letters by using Easy English (see Appendix 9 – Other Resources p. 62) and making reminder phone calls;
- booking an extended consultation to accommodate possible complexity;
- trying to avoid long waiting times in high stimulation environments;
- arranging appointments which accommodate the person's preference and facilitate accessibility, such as time, location or any other health considerations;
- avoid cancelling appointments at short notice and where possible, prepare the person for change;
- preparing for communication needs, for example, ensuring that their preferred communication system is available during the appointment, and where necessary, arranging an interpreter;
- identifying and accommodating other physical support needs such as those arising from mobility and sensory impairments;

- establishing who will be accompanying the person with an ID and accommodating them in the consultation;
- identifying and communicating with those who can provide an accurate history, further information, or data related to the presenting problem; or
- with consent, obtaining and reviewing detailed background health and mental health information from a range of relevant sources.

Effective Communication

People with an ID and health professionals have identified poor communication as a barrier to accessing health care. People with an ID often experience communication difficulties. While these are more apparent in people with more severe levels of disability, even a person with mild ID may have difficulty understanding abstract concepts or complex questions. Effective communication requires considerable thoughtfulness, time, attention to the person and their needs and adaptation of the professional's communication. The person’s age and cultural background should also be taken into account during any interaction.

“Detailed review of historical information including developmental, medical and medication histories in addition to specialist reports, school and psychological reports can be illuminating.”

– Psychologist, ID mental health service
Implications for Mental Health Services

Developing mental health services that are accessible for people with an ID can be achieved by:

1) making adaptations to existing services;
2) utilising collaborative and multi-disciplinary approaches;
3) providing appropriate education and training; and
4) introducing new systems.

The following section details adaptations that mental health providers could make to their existing services to improve accessibility for people with an ID. For each broad service category, adjustments and strategies at organisational and individual levels are suggested. These adaptations are divided into key roles and responsibilities and further improvement strategies for a comprehensive health service.

Some mental health service providers may not strictly identify within one classification and may fall across the various health service categories identified.

IMPLICATIONS FOR ALL MENTAL HEALTH SERVICE PROVIDERS

The following responsibilities have been identified for all mental health professionals and organisations which treat people with an ID and co-occurring mental disorders:

- Provide accessible mental health services that are person-centred, and recognise the right that persons with an ID have to accessing treatment as core business. This includes:
  - providing a physical environment or outreach service that is accessible to a person with an ID and their care(e), and
  - providing information for consumers and their families using easy-to-understand language or using augmentative and alternative communication where appropriate.
- Work in a collaborative and coordinated manner with key disability and related specialist supports. This includes, but is not limited to:
  - family and care(e),
  - teachers and education sector staff,
  - case managers and support workers,
  - primary care providers,
- specialist medical services including private, public and specialised ID mental health service providers,
- allied health practitioners, for example, those providing behaviour support; and
- specialist cultural services including Aboriginal and Torres Strait Islander and culturally and linguistically diverse organisations.

- Support the individual’s optimal functioning and their return to full capacity.
- Ensure linkage to the client’s primary health care practitioner to facilitate continuity of care.
- Facilitate optimal access to services by utilising mechanisms such as Telehealth (see Glossary p.42) to ensure appropriate care and support is received.
- Maintain awareness of appropriate consumer and carer advocacy services.
- Foster the development of skills in ID mental health. This includes either through the provision of education and access to training resources at an organisational level or through attendance and pursuit of these skills at an individual level.
Tools for Inclusive Practice

The following section provides a selection of tools and resources which have a specific focus for people with an ID requiring mental health services and support.

APPENDIX 1: ASSESSMENT AND DIAGNOSTIC TOOLS

People with an ID and mental health issues should receive comprehensive, timely and accurate assessment with regular review of their progress provided to the service user and their carer(s). A range of assessment tools and resources which may assist in providing accurate and timely assessments of people with an ID are provided below.


The ABAS-II is an adaptive behaviour assessment tool which covers the lifespan with age-specific versions.

Assessing Mental Health Concerns in Adults with Intellectual Disabilities – A Guide to Existing Measures

http://dx.doi.org/10.1016/j.jins.2011.04.005
This resource provides an overview of the various instruments used to assess mental health concerns in adults with an ID.

Camberwell Assessment of Need for Adults with Developmental and Intellectual Disabilities (CANDID)

http://www.rcpsych.ac.uk/publications/books/cpp/1901242994.aspx
The CANDID has been developed and tested by a multidisciplinary team of the Institute of Psychiatry in London. This instrument has been designed for mental health staff to undertake a comprehensive assessment for use with adults with all levels of ID.

The Developmental Behaviour Checklist

www.med.monash.edu.au/spopp/research/devpsych/dbc.html
The Developmental Behaviour Checklist is a suite of instruments for the assessment of behavioural and emotional problems of children, adolescents and adults with developmental and intellectual disabilities.


www.dm-id.org
A manual designed to be an adaptation of the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV) developed by the National Association for the Dually Diagnosed, in association with the American Psychiatric Association.

DC-LD: Diagnostic Criteria for Psychiatric Disorders for use with Adults with Learning Disabilities

www.rcpsych.ac.uk/publications/collagepapers/op/ep60.aspx
A classification system providing operationalized diagnostic criteria for psychiatric disorders, intended for use with adults with moderate to profound learning disabilities. It may also be used in conjunction with the ICD-10 and DSM-IV manuals in a complementary way, when working with adults with mild learning disabilities. Suitable for use by professionals trained in psychiatric diagnosis.
Available online
3dn.unsw.edu.au
Free e-learning
intellectual disability mental health

www.idhealtheducation.edu.au

- Introduction to Intellectual Disability
- Living with Intellectual Disability
- Changing Perspectives of Intellectual Disability
- Introduction to Mental Disorders in Intellectual Disability
- Communication: the basics
- Improving your Communication
- Assessment of Mental Disorders in Intellectual Disability
- Management of Mental Disorders in Intellectual Disability
- Coming Soon:
  - interagency work
  - emergency presentations
  - carer intro to mental disorders in people with ID
  - legal and ethical Issues
  - challenging behaviour
- Coming later in 2015:
  - Disability worker modules
Intellectual Disability Mental Health (IDMH) Core Competencies Manual: for NSW Public Mental Health Services

For project status:
Coming Soon: IDMH Core Competency Framework

Intellectual Disability Mental Health Core Competency Framework

A Manual for Mental Health Professionals

Draft for Approval by MH-CYP

April 2015

The Department of Developmental Disability Neuropsychiatry,
UNSW Australia

Julian Trollor, Janelle Weise and Claire Eagleson

This document is not for distribution
MAKING SERVICES ACCESSIBLE TO PEOPLE WITH AN INTELLECTUAL DISABILITY

PREPARING: Take the time to prepare for working with a person with an intellectual disability by finding out about their strengths, and the support they may require to actively participate.

ADJUSTING COMMUNICATION: Determine the person’s preferred communication style, and appropriately adapt your communication style to meet their needs.

LEARNING & INTEGRATING knowledge into practice: Learn about Intellectual Disability Mental Health and use your new knowledge to improve practice.

ENGAGING SUPPORT
NETWORKS: Identify the person’s support network, and when appropriate to do so, work with them at all stages of service delivery.

SEEKING SUPPORT: Identify and actively seek support from specialist intellectual disability mental health professionals, when required.

FACILITATING SUPPORTED DECISION-MAKING: Facilitate supported decision and give priority to the persons expressed wishes, as far as possible.

COLLABORATING across agencies: Work with partner organisations to deliver a seamless service to people with an intellectual disability, their families, and support networks.

Making Information ACCESSIBLE: Provide information to the person with an intellectual disability, their family, and support networks in accessible formats, at all stages of the clinical process, acknowledging that the format may be different for different skin tones.

Knowing what SKILL SETS are available: Be aware of the different skills and approaches available in the mental health and disability sectors, and use this knowledge to facilitate collaborative work.
National Mental Health Commission Report

• Significant mention of ID
• Recognition of ID as a minority group of need
• Several possible avenues for capacity development
Maia and her Girlfriends from High School often get together for afternoon tea. Sometimes it’s a party. Last time the theme was pink so Maia put a pink ribbon in her hair and went with her two sister, Alexis. Maia enjoys listening to books on her iPod and likes receiving a hand massage from her young carers, who take her shopping or to the park.

It’s a good life, says her mother, Michelle. Maia uses a wheelchair because of her cerebral palsy and has mild intellectual disability. She’s valued in her community and adored by her family, which includes her father and younger brother.

Usually a happy, chirpy person with a infectious sense of humour and an enthusiasm for life, small things can change suddenly. Maia struggles with changes and has had two protracted episodes of delirium, which revealed entrenched prejudices in the health system.

"The first time it was completely out of the blue," says Michelle. "She didn’t know her own name and she didn’t recognize her own mother. She was saying things that were really distressing." Maia was also screaming, obviously in pain.

Michelle struggled to convince the hospital how unusual this behaviour was. "Initially we came up against an attitude of, ‘isn’t she always like that?’" Michelle recalls.

She found it "profoundly insulting" that Maia’s whole lifestyle, personality and network of relationships were debelied, and her daughter’s distress disregarded amid the low expectations the doctors and nurses had for someone with a disability.

Michelle, the lead doctor, found a specialist clinic that looks holistically at mental health and other needs of people with an intellectual disability. Though not a paradise it provides a strong starting point to identify the physical problems behind much of Maia’s distress.

Conflict with the treating team resulted. The hospital identified and treated some physical problems to discharge Maia, despite her continuing psychological distress and confusion. "I said, 'you can’t just send her home like this.'" says Michelle. "They told us to put her in a nursing home. We were overwhelmed by that... They were declaring her out of existence.

Michelle, her sister, doctor, found a specialist clinic that looks holistically at mental health and other needs of people with an intellectual disability. Though not a paradise it provides a strong starting point to identify the physical problems behind much of Maia’s distress.

Michelle went on to say that without her professional expertise, she might never have been able to navigate a health system that insists on viewing people through their principal diagnosis.

"I work in a public mental health service and when clients are physically unwell and they go into hospital they get the same nonsense," Michelle says. "It’s a disability breakdown. People see one disability and they don’t see anything else. If it was Maia’s leg in a cast, people would go to the end of the earth to help her, as she should. It’s an error of thinking, and it can be a fatal error of thinking."
NSW Mental Health Commission: Strategic Plan

LIVING WELL
A STRATEGIC PLAN FOR MENTAL HEALTH IN NSW 2014 – 2024

Actions

7.3.1 Ensure that Local Health Districts and community-based services implement Accessible Mental Health Services for People with an Intellectual Disability: A Guide for Providers.

7.3.2 Ensure that adequate training in the recognition, assessment, referral pathways and treatment for people with an intellectual disability and mental illness is given to all staff in mental health and disability services. Such training will need to include particular reference to adopting reasonable adjustments in clinical approaches and adopt a recovery-oriented approach.

7.3.3 As part of the NSW implementation plan for the National Disability Insurance Scheme, develop strategies to change from the present partnership between NSW Health and other state services with Ageing, Disability and Home Care to one with the community-managed and private sectors. This will need to take account of the impact on:
- joint projects
- memorandums of understanding
- co-developed guidelines
- relationship management
- dispute resolution
- systemic and strategic planning.

7.3.4 Develop a recovery-oriented model of care for the provision of public mental health services to people with an intellectual disability that:
- builds the capacity of mainstream community and inpatient mental health services
- increases specialist capacity to meet more complex needs
- facilitates joint planning by disability services, mental health and other relevant services, including in relation to referral and treatment pathways and collaborative responses where intellectual disability and mental disorders coexist.

7.3.5 Develop accessible information for people with an intellectual disability and their families and carers about mental health services.

Future direction
A sharper focus is required on policy and program development for the mental health needs of children and young people with an intellectual disability. This should include tailored prevention and early intervention programs and services that offer timely and skilled mental health assessment and intervention.
What Could Local Capacity Building Look Like?

• Enhanced joint disability/mental health working groups
• Specific mental health resources for people with ID, and their carers
• Service pathway and referral maps
• Managerial support for enhanced focus on training of mental health sector
• Roll out of IDMH core competencies when released
• Collation of local resources and specialists
• Developing a network of skilled providers: GPs, psychologists, psychiatrists, physicians, allied health practitioners
• Specialist IDMH team within mainstream mental health services
• Hospitalisation protocols for people with multiple or complex disabilities
• Development of specific expertise and capacity within large NGOs
• Community hub model for the conduct of joint multidisciplinary clinics
• Preventative mental healthcare in a community setting
Summary

• People with ID experience significant health inequalities
• People with ID require timely access to effective and high quality mental health care
• Access to effective mental health care can be improved
• Improved access requires a multilevel solution
• Guiding principles are apparent
• There are key priorities for reform
• There are individual and corporate responsibilities
• Improvement must be quantifiable (people, workforce, system, policy)
Funding Sources

**Funding: Core**
- Ageing Disability and Home Care | Family and Community Services NSW
- UNSW Medicine

**Funding: Research and Projects**
- NSW Ministry of Health & Related Organisations
  - MHDAO, MH Kids, HETI, ACI ID Network
- Australian Government Department of Health and Ageing
- Australian Research Council (ARC)
- National Health and Medical Research Council (NHMRC)
- NSW Institute of Psychiatry
- Autism CRC
About Us

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