Accessible mental health services for people with intellectual disability

*Implications for disability service providers*

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Acknowledgements/Declarations

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

Funding: Research and Projects
• NSW Ministry of Health
  – MHDAO
  – MH Kids
  – HETI
• Australian Government Department of Health and Ageing
• Australian Research Council (ARC)
• National Health and Medical Research Council (NHMRC)
• NSW Institute of Psychiatry
• ACI ID Network
Accessible mental health services for people with intellectual disability

Implications for disability service providers

- The clinical need
- The supports
- Complementarity: mental health and disability
- IDMH Initiatives: relevance to disability sector
- Future landscape
Intellectual Disability Mental Health

- Intellectual Disability
  - About 1.8% of the population
  - About 400,000 Australians
- Over-representation of mental disorders
  - Conservative estimates for adults/children with ID 2.5/3-4x
- Access to mental health supports and treatments is limited
- High impact for people with ID, families and carers
- Multiple vulnerabilities
- Complexity
## Vulnerabilities to Mental Disorder

### Social risk factors
- Social isolation
- Social adversity
- Adverse life events
- Stigma
- Communication difficulties
- Reduced social and interpersonal skills
- Absence of meaningful occupation

### Psychological risk factors
- Maladaptive/ineffective coping strategies
- Feeling overwhelmed
- Stress and worry
- Low self-confidence/self-esteem; self-doubt
- Emotional regulation skills
- Capacity to process multiple sensory and mental stimuli

### Biological risk factors
- Physical inactivity
- Poor diet
- Multiple health conditions
- Polypharmacy
- Epilepsy
- Head injuries
- Family history of mental disorder
- Genetic anomalies – eg Velocardiofacial syndrome is associated with higher rates of mental disorder, particularly schizophrenia
- Severe physical disability
- Multiple disabilities
- Sensory impairments, eg problems with hearing and vision

### Various combinations of social, psychological or biological risk factors
- Social and communication impairments, eg those associated with autistic disorder
- Family stress or conflict
- Interpersonal difficulties
- Chronic pain
- Atypical physical appearance
- Motor impairment
- Lower IQ
- History of trauma and abuse
- Experiences of loss, grief, or unwanted life changes
- Being easily manipulated
- Deprivation or neglect
- Below average achievement
Access to MH Services and Supports

Significant Barriers
eg Einfeld & Tonge

Policy

Historical

Silos

Workforce and skills

Individual and Carer

Conceptual
Elements and Interconnections in Mental Health Services Provision to People with an Intellectual Disability (ID)

Commonwealth

Patient Controlled Electronic Health Record

Medicare Benefits Schedule Funded

Primary Care

Private Psychiatrists & Psychologists + Headspace

Disability Services

DisabilityCare (NDIS)
Community Support
Behaviour Support
Supported Accommodation

University Based Services
Education & Training
Clinics
Research

Activity Based Funding

Local Health District
Mental Health

Psychiatric Emergency Care

Community Mental Health

Acute & Crisis Care

Specialist ID Mental Health

Mental Health Intake

Emergency Dept

Specialist ID Health

Psychiatric Ward

Acute Rehabilitation

Consultant Liaison Psychiatry

General Hospital Wards

Community

Hospital

Legend

- Existing Mental Health elements and links
- Proposed additions for Intellectual Disability

Tony Florio 2013
Elements and Interconnections in Mental Health Services Provision to People with an Intellectual Disability (ID)

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Activity Based Funding

State

Legend

Existing Mental Health elements and links

Proposed additions for Intellectual Disability

Tony Florio 2013
Supports for People with an Intellectual Disability

- Disability supports
- Health
- Schools
- Community services
- Housing
- Legal (legal aid, police, JJ, DCS)

Individual & Families
3DN Strategic Plan 2013-2015

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

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

**Guiding Principles**
• Human rights
• Equity in mental health care
• Excellence and academic leadership
• Innovation in health services
• Collaboration
• Ethical conduct

*I commend 3DN’s Strategic Plan 2013 to 2015, which provides a powerful intellectual and professional framework on which a person-centred approach to support can be built.*

John Feneley, NSW Mental Health Commissioner
## Priorities

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<td>Promote greater integration between disability and mental health systems and improve access for people with an intellectual or developmental disability.</td>
<td>Highlight the importance of initiatives and funding in intellectual and developmental disability mental health.</td>
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Priorities

**STRATEGIC PRIORITY 1**
• Improve mental health outcomes for people with an intellectual or developmental disability.

**STRATEGIC PRIORITY 2**
• Increase the knowledge, skills and confidence of the health workforce to deliver quality care and support to people with an intellectual or developmental disability.

**STRATEGIC PRIORITY 3**
• Promote greater integration between disability and mental health systems and improve access for people with an intellectual or developmental disability.

**STRATEGIC PRIORITY 4**
• Highlight the importance of initiatives and funding in intellectual and developmental disability mental health.
Clinical Scenario 1: Low Complexity
Clinical Scenario 1: Low Complexity

Person with Mild ID & MD → Service Contact → Intervention → Outcome

Health Service Strengths:
- Familiar clinical domains
- Standard presentations
- Early Intervention
- Proactive case management

Health System Enhancements:
- Defined service pathway
- Accessible clinics
- Access to specialist IDMH expertise

Health Practitioner Supports:
- Skills & training
- Reviews with specialist IDMH
- Enhanced liaison with disability services
Clinical Scenario 1: Low Complexity

Person with Mild ID & MD → Service Contact → Intervention → Outcome

**Disability Service Strengths**
- Person centred approach
- Holistic framework
- ‘Connectivity’ to other systems

**Disability System Enhancements**
- Defined service pathway
- Access to clinical services
- Access to specialist IDMH expertise

**Disability Practitioner Supports**
- Skills & training
- Behavioural supports
- Enhanced liaison with health services

Person with Mild ID & MD

Intervention

Outcome

Person centred approach
Holistic framework
‘Connectivity’ to other systems

Defined service pathway
Access to clinical services
Access to specialist IDMH expertise

Skills & training
Behavioural supports
Enhanced liaison with health services
Clinical Scenario 2: Medium Complexity

Person with ID & MD
- ASD
- Communication
- Medical condition/s
- Supports
- Forensic

Service Contact
- Community
- Acute care
- ED
- Police

Intervention
- Range
- Cross sector

Outcome
- Improved function & QOL
- Substantially reduced costs
Clinical Scenario 2: Medium Complexity

Person with ID & MD
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Service Contact
- Community
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Intervention
- Range
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Outcome
- Improved function & QOL
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Health Service Strengths
- Local IDMH working groups
- Risk management
- Multidisciplinary Assessment
- Some partnerships with local or regional disability services.

Health System Enhancements
- Viewing people with an ID as core business
- Ensuring access to training for staff
- Collation of local and regional resources
- Identified care pathways
- Development of accessible information for consumers and their families.

Health Practitioner Supports
- Skills and training to assess & manage complexity
- To liaise and engage specialist ID/MH practitioners
- To work across sectors

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Outcome
- Improved function & QOL
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Disability Service Strengths
- Local IDMH working groups
- Multidisciplinary
- Some partnerships with local or regional disability services.

Disability System Enhancements
- Viewing people with Mental Illness as core business
- Ensuring access to training for staff
- Collation of local and regional resources
- Identifying local care pathways
- Assisting health to develop accessible information for consumers and their families.

Disability Practitioner Supports
- Skills and training to assess & manage complexity
- To liaise and engage specialist ID/MH practitioners
- To work across sectors

Outcome
- Improved function & QOL
- Substantially reduced costs
Clinical Scenario 3: High Complexity

Person with ID & MD
- Severe-profound ID
- Behavioural disturbance
- Medical comorbidities
- Specific Syndrome

Service Contact
- Community
- Acute
- ED
- Specialist Clinic

Intervention
- Specialised assessment
- Multidisciplinary

Outcome
- Improved function & QOL
- Substantially reduced costs
Clinical Scenario 3: High Complexity

Person with ID & MD
- Severe-profound ID
- Behavioural disturbance
- Medical comorbidities
- Specific Syndrome

Service Contact
- Community
- Acute
- ED
- Specialist Clinic

Intervention
- Specialised assessment
- Multidisciplinary

Outcome
- Improved function & QOL
- Substantially reduced costs

Health Service Strengths
- Local IDMH working groups
- Untapped staff resource
- Small number of specialised teams

Health System Enhancements
- Specific specialist capacity
- In reach to disability teams, schools, special education
- Team to engage in education & capacity building

Health Practitioner Supports
- Skill development to advanced level
- In-depth knowledge of interactions between health/MH/Behaviour
- High level expertise in management
- Capacity to train

Person with ID & MD
- Severe-profound ID
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Clinical Scenario 3: High Complexity

**Person with ID & MD**
- Severe-profound ID
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**Service Contact**
- Community
- Acute
- ED
- Specialist Clinic

**Intervention**
- Specialised assessment
- Multidisciplinary

**Outcome**
- Improved function & QOL
- Substantially reduced costs

**Disability Service Strengths**
- Local IDMH working groups
- Specialised response to behavioural aspects
- Strong forensic expertise

**Disability System Enhancements**
- Specific assessment facility?
- Hub which engages mental health
- Team to engage in education & capacity building

**Disability Practitioner Supports**
- Skill development to advanced level
- In-depth knowledge of interactions between health/MH/Behaviour
- Development of high level expertise in management

**Intervention**
- Person with ID & MD
- Disability Service Strengths
- Disability System Enhancements
- Disability Practitioner Supports

**Outcome**
- Improved function & QOL
- Substantially reduced costs
Capacity Building Projects

- ADHC Funded IDMH Fellowships
- Training pathways in IDMH
- National audit of ID health content in Australian Medical and nursing schools
- NSW Mental Health Staff Survey
- IDMH Core Competencies Project
- Data linkage
- National Guide for mental health services
- IDMH e-learning
NSW ID Mental Health Data Linkage Projects

- Pilot data: ADHC/Ambulatory MH data 2011-2013
- NSW MH and ADHC linkage 2012-2013
- NHMRC Partnerships grant linkage- 2014+
Pilot IDMH Data Linkage Project NSW

- 2011 - pilot test of linkage (ADHC Funding)

- Mental Health Ambulatory data + ADHC Disability Minimum Dataset (MDS) 2005-2010.

- Representative area of NSW:
  - South Eastern Sydney, Illawarra Shoalhaven, Sydney and South Western Sydney Local Health Districts (formerly Area Health Services) with Metro South and Southern ADHC Regions.
Key Findings

- People with ID compared to those without:
  - Under represented in MH-AMB (only 1.2%)
  - Mean age of 35.3 years
  - More likely to be treated for chronic psychotic disorder & PD
  - Less likely to be treated for more common disorders such as: major depression & adjustment disorders.
  - No difference in bipolar or anxiety disorders.

- Uncertainty in diagnosis - ‘Unknown category’

- Complexity of those with ID apparent from service use profile:
  - 1.8x more face-to-face contacts than those without ID.
  - 2.6x as long than those without ID.
NSW IDMH data linkage - Current

- 2012 – State-wide linkage
  (Mental Health & Drug & Alcohol Office (MHDAO), NSW Ministry of Health funding).

- 2005 - 2016
  Longitudinal, establishing annually refreshed link feed

- Disability Minimum Dataset (MDS)
- Admitted Patient Data Collection (APDC)
- Mortality Data (ABS and RBDM)
- Emergency Department Data Collection
‘Accessible Mental Health Services for People with ID: A Guide for Providers’

The Goal

- To improve mental health service access for people with an intellectual disability by developing a guiding framework of action for all front line mental health service providers.
Methodology

- Core Reference Group formation
- Background research and collation
- Draft sections for CRG consultation
- Focus group consultation
- Second Draft and circulation
- Final Draft
- Publication
### Guiding Principles

- Rights
- Inclusion
- Person centred approach
- Promoting independence
- Recovery-oriented practice
- Evidence based

### Key Components

- 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
- Inclusion in policy
Key roles and responsibilities for all mental health professionals and organisations:

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<td>• Providing information using augmentative and alternative communication or in Easy English where appropriate to consumers and their families.</td>
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<td>• Working in a collaborative and coordinated manner with key disability and related specialist supports including, but not limited to:</td>
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<td>• allied health practitioners, i.e. those providing behaviour support.</td>
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<td>• Supporting the optimisation of functioning for the individual and their return to full capacity as appropriate.</td>
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- Working in a collaborative and coordinated manner with key disability and related specialist supports including, but not limited to:
  - family members, formal and informal carers;
  - teachers and education sector staff;
  - primary care providers;
  - specialist medical services including private, public and specialised ID mental health service providers and;
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- Supporting the optimisation of functioning for the individual and their return to full capacity as appropriate.
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### Key roles and responsibilities of Public Mental Health Services: For the Organisation

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<th>Disability</th>
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<td>• To competently conduct a comprehensive mental health assessment.</td>
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Further enhancement of Public Mental Health Services would include

**For the Organisation**

- Fostering staff development of skills in ID mental health through the provision of education and access to training resources
- Awareness and engagement as appropriate with the academic sector for the purposes of facilitating links to highly specialised expertise, research and training opportunities.
- The development of joint initiatives between local disability and mental health services including:
  - the capacity for the conduct of joint assessments of people with an ID and possible mental health disorder;
  - the capacity for priority referral of urgent cases from disability or health sector to one another;
  - the establishment of regular meetings between designated mental health and disability staff to discuss specific cases;
  - the conduct of joint training and education initiatives;
  - the establishment of pathways for case escalation;
  - the development of long-term accommodation models for people with an ID and mental disorders, including those with challenging behaviours;
  - the development of assertive outreach and inpatient assessment and treatment models for people with an ID and co-occurring mental disorders including challenging behaviours.
- Identification of expertise in ID mental health within existing public mental health sector staff who can act as ‘ID mental health champions’ in each local area.
- Suggested inclusion from survey ID:12 / PW.
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Further enhancement of Public Mental Health Services would include

For the Individual Health Professional

- Skill development in ID mental health to an advanced level, including:
  - an in-depth knowledge of the interactions between health and mental health conditions and challenging behaviour;
  - high level expertise in the management of mental disorders in people with ID, including an awareness of the role and application of non-pharmacological treatments;
  - the development of an in-depth knowledge of functional assessment and applied behaviour analysis;
  - detailed understanding of the application of diagnostic and classification systems for mental disorders in people with an ID.
- Contribution to capacity building including to the training of health professionals in ID mental health.
Further enhancement of Public Mental Health Services would include

*For the Individual Health Professional*

- Skill development in ID mental health to an advanced level, including:
  - an in-depth knowledge of the interactions between health and mental health conditions and challenging behaviour;
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  - detailed understanding of the application of diagnostic and classification systems for mental disorders in people with an ID.
- Contribution to capacity building including to the training of health professionals in ID mental health.
NSW IDMH Core Competencies Project Aims

- To determine the attitudes, confidence, skills and knowledge of the NSW mental health workforce in relation to delivering services to people with an ID.
- To identify the training needs of the NSW public mental health workforce in the area of IDMH.
- To develop, implement and evaluate an IDMH core competencies manual.
Competencies Project Overview

• Funded by MH-Kids
• Advisory group
  • Representatives from across major age groups
  • IDMH experts
• Two key elements
  • Part 1: On-line staff survey
  • Part 2: IDMH core competencies manual
Free e-learning
intellectual disability mental health

www.idhealtheducation.edu.au

Ministerial Launch Monday 22 July 2013

- 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
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Disability Sector Modules: Funding Required
Free e-learning
intellectual disability mental health

www.idhealtheducation.edu.au

Opportunity for Full Time Project Officer

- Start ASAP
- Level 6 Project Officer
- Further Module Development, Project Development
Development of Local Capacity in IDMH

- ADHC/MHDAO Joint IDMH Committee
- Local IDMH Working Groups
  - Vehicle of future change
  - Enhancing scope of activities
  - Auditing capacity; reviewing policy and procedures
  - Promoting training and education
  - Defining clinical pathways through services
  - Up skilling key staff
- Consider development of local Specialised IDMH team in each LHD
  - Use of the NSW IOP Fellows
  - Fractional psychiatrist, registrar, CNC
NDIS & DisabilityCare Australia

• An opportunity to get things right
• Person centred & promoting independence
  • IDMH capacity in mainstream
• Potential for collaboration in areas of complexity
  • Community hub (ADHC/Health/NGO)
• Potential to cross link data from NDIS and health
  • Importance of e-health records
Conclusions

• Considerable clinical need
• Considerable potential for joint capacity building
• Some projects underway
• Considerable momentum
• NDIS:
  – Potentially destabilising
  – opportunities
• Preferred model needs to emerge