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Chair, Intellectual Disability Mental Health Mental Health (IDMH)

Practical Guidance for Justice Health

Head, 3DN

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Main Points

• What is ID?
• Implications for health and mental health
• Barriers to access to health care
• Relevance to Custodial Healthcare
• Reasonable adjustments to clinical practice
• Practical Resources
• Questions
What is an Intellectual Disability?

• Below average intelligence
  IQ <70, ie at least 2 standard deviations below mean)
PLUS
• deficits in adaptive behaviours
AND
• onset before the age of 18

Somewhere between 0.5-3% of the population (1.8%)

Borderline Intellectual Functioning (IQ 70-84)
• ~ 13% of the population
Other Terminology

- Intellectual Disability
- Intellectual Handicap
- Mental Retardation
- Learning Disability
- Developmental Disability
- Intellectual AND Developmental Disability
- **A Person With an Intellectual Disability**
Classification

- Profound (IQ < 20/25) Affects 1-2%
- Moderate (IQ 35/40 – 50/55) Affects ~10%
- Severe (IQ 20/25 – 35/40) Affects 3-4%
- Mild (IQ 50/55 – 70/75) Affects ~85%

## Causes of intellectual disability

<table>
<thead>
<tr>
<th>Conception</th>
<th>Gestation</th>
<th>Perinatal</th>
<th>Childhood</th>
<th>18</th>
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</thead>
</table>
| **Genetic/chromosomal disorder** | Chromosomal disorders  
- Tri21  
- Fragile X  
- Other chromosome disorders  
**Syndrome disorders**  
- Tuberous sclerosis  
- Muscular dystrophies  
**Inborn errors of metabolism**  
- PKU  
- Lesch-Nyhan  
- Wilson’s disease |  |  |  |
| **Possible genetic or environmental cause** | Developmental brain abnormalities  
- Polymicrogyria  
- Spina bifida  
**Syndrome disorders**  
- Craniofacial synostosis | Prematurity  
- Intracranial haemorrhage  
- Respiratory distress  
- Kernicterus | Seizure disorders  
- Epilepsy  
**Degenerative disorders**  
- Childhood disintegrative disorder  
- Juvenile Parkinson’s disease |  |  |
| **Insult to the brain** (environmental – trauma, toxin, virus or bacterial infection, malnourishment, hypoxia) | Varicella infection  
- Irradiation  
- Maternal malnutrition  
- Placental insufficiency  
- Fetal alcohol syndrome | Placental insufficiency  
- Obstetric trauma  
- Head trauma | Environmental deprivation  
- Head injury  
- Infection  
- Post-infectious demyelinating disorders  
- Toxic metabolic disorders eg lead poisoning  
- Malnutrition |  |  |
Impact of ID – Health

• Lower life expectancy\(^1\)
  o Decreases with increasing disability
  o From 10 years, to 20 years lower for those with severe ID
• Higher morbidity\(^2,3\)
• Lower rate of disease detection and treatment\(^2,3\)

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General health challenges – ID

- Dental disease (7x)
- Vision impairment & eye disorders (7-20x)
- Hearing impairment
- Thyroid diseases
- Epilepsy
- GERD
- Osteoporosis
- Hospitalisation (2x)
- Serious injury (2x)

- Mobility problems
- Multiple chronic complex disorders
- Polypharmacy
- Lifestyle related
  - Overweight & obesity
  - Constipation
  - ↓ Physical fitness
Health status & Aetiology of ID

• Specific disorders associated with ID can have health implications. Common egs:
  – Down syndrome
  – Tuberous sclerosis
  – Fragile X syndrome
Intellectual Disability Mental Health

- People with an intellectual disability experience an over-representation of mental disorders
  - Conservative estimates for adults/children with ID 2.5/3-4x
- At any one time, an estimated 20-40% of people with an ID will be experiencing a mental disorder of some kind.
- Access to mental health supports and treatments is limited
- High impact for people with ID, families and carers
- Complexity
- Multiple vulnerabilities
ID Mental Health across the Lifespan

• predisposition to mental ill health across the lifespan
  – Children: neurodevelopmental disorders
  – Younger persons: Schizophrenia over-represented 2-4 x, earlier onset in people with an ID.
  – Older persons: higher rates of dementia.
Supports for People with an Intellectual Disability

Disability supports

Individual & Families

Health

Schools

Financial

Community services

Legal (legal aid, police, JJ, DCS, JH)

Housing
Vulnerabilities to Mental Disorder

**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

**Social risk factors**
- Social isolation
- Social adversity
- Adverse life events
- Stigma
- Communication difficulties
- Reduced social network
- Absence of support

**Psychological risk factors**
- Maladaptation
- Feeling of isolation
- Stress and anxiety
- Low self-esteem
- Emotional problems
- Capacity

**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

Silos

Individual and Carer

Conceptual

Workforce and skills

Historical
Effect of Level of ID & Communication Skills

• Level of ID + presence of any associated communication difficulties
  – affect how symptoms of mental ill-health manifest in people with an ID.

• People with milder ID and good communication skills:
  – able to describe what they are experiencing
  – typically present in a manner familiar.

• Presentation atypical in:
  – more severe ID
  – people with communication difficulties
  – mental disorders may present as problematic behaviours
  – diagnostic overshadowing
Behaviour/ Psychiatric Status & Aetiology of ID

• Behavioural Phenotypes [characteristic patterns of social, linguistic, cognitive and motor features consistently associated with a biological or genetic disorder].
  – Prader-Willi Syndrome
  – Mowat-Wilson Syndrome

• Specific psychiatric vulnerability egs
  – Prader-Willi Syndrome
  – Down syndrome
  – Fragile X syndrome
Borderline Intellectual Functioning

- ~13% of the population
- A ‘health metacondition’ which requires intervention
- Related neurodevelopmental conditions
- Associated with behavioural disorder
- Strong psychosocial determinants
- Association with adult antisocial behaviours
ID and Offending

- Overrepresentation of people with ID in the CJS
- Suicide in prisoners with ID may be over-represented (Shaw et al 2003)
- A group at risk of:
  - victimisation
  - mental illness
- Deinstitutionalisation results in challenges
- Increased interest in court diversion and other non-custodial options for this group
- Need for training of mental health & prison staff
How Common is ID in CJ Settings?

- Large variations on prevalence of ID within CJS (2-40%). (See Jones J, Int J Offender Ther Comp Criminol 2007;51:723-733; Holland JIDD 1991;17:119-126)
- 19% prevalence of ID in men in remand in Quebec (Chevrier 1993)
- 10-12% in magistrates court in NSW (Vanny et al JIDR 2009;53(3):289-297)
- Large systematic review (Fazel et al Int J Law & Psychiatry 2008;31:369-373); only 0.5-1.5% of prisoners had ID
Offending Behaviours are Complex in ID

Severity of ID
Adaptive skills

- Axis I mental disorder
- Challenging behaviour
- Personality
- Psychosocial disadvantage
- Physical health

Offending behaviour
Relationship Between Level of ID, Offending behaviour and Setting

- Offending behaviour
- Courts
- Remand
- Jail sentence

Severe-Profound ID
Mod ID
Mild ID
Borderline
Reducing Vulnerability to Harm in Adults With Cognitive Disabilities in the Australian Criminal Justice System

Eileen Baldry, Melissa Clarence, Leanne Dowse, and Julian Trollor
University of New South Wales, Sydney, NSW, Australia

• Complexity (dual/co-morbid diagnoses and multiple combinations)
  – Associated with higher rates of re-offending, convictions, imprisonments
• Those with cognitive disability had poor school education and low disability service recognition and support
• Recognition of the disability and provision of appropriate supports led to improved outcome
Australian Prisoners with ID/Borderline IF

- More likely to:
  - Be Male
  - be Indigenous
  - Have had unstable accommodation
  - Have had contact with JJ
- Have poor mental health
  - Lifetime prevalence 52% (adjusted OR 1.7)
  - Current prevalence 37% (adjusted OR 2.1)
- Have higher psychological distress scores (K10)
- Have higher psychototropic medication rates

Shannon Dias, Robert S Ware, Stuart A Kinner and Nicholas G Lennox
Co-occurring mental disorder and intellectual disability in a large sample of Australian prisoners. Aust N Z J Psychiatry 2013 47: 938
Australian Prisoners with ID/Borderline ID

• More likely to have:
  – poorer self reported health
  – Epilepsy
  – Hearing impairment
  – Obesity

• Less likely to have engaged in preventative health measures such as disease screening, vaccinations etc
## 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

**Approach to People with an ID**
‘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 Issues for Health Professionals

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<td>• Competent mental health assessments.</td>
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<td>• Appropriate management plans.</td>
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<td>• Timely reviews.</td>
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<td>• Regular review of psychotropic medications and monitoring any potential side-effects.</td>
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<td>• Identification and familiarity with care pathways</td>
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<td>• Partnerships with local or regional disability services.</td>
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<td>• Availability of specialised ID health and mental health services.</td>
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<td>• Referral as appropriate for a second opinion.</td>
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<td>• Skill development in ID mental health</td>
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Key Issues for Services Include:

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<td>Recognition and promotion of the rights of people with an ID to access appropriate mental health services.</td>
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<td>Viewing the mental health of people with an ID as core business in mental health services.</td>
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<td>The development of partnerships with local or regional disability services.</td>
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<td>An understanding of the referral processes to disability and related services, including the development of networks and partnerships with local disability services.</td>
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<td>The development of staff resources outlining the availability of, and access to, local or regional specialised ID health and mental health services.</td>
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<td>The development of identified care pathways through typical service components.</td>
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<td>The development of accessible information (e.g. Plain English, modified or Easy English materials) where appropriate to consumers and their families.</td>
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<td>Fostering staff development of skills in ID mental health through the provision of education and access to training resources.</td>
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<td>Awareness and engagement with the academic sector.</td>
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<td>The development of joint initiatives between local disability and mental health services including:</td>
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<td>* priority referrals of urgent cases from disability or health sector to one another;</td>
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<td>* the establishment of regular meetings between designated mental health and disability staff to discuss specific cases;</td>
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<tr>
<td>* the conduct of joint training and education initiatives;</td>
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<td>* the establishment of pathways for case escalation;</td>
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<td>* the development of long-term accommodation models for people with an ID and mental disorders, including those with offending behaviours;</td>
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<td>* Identification of expertise in ID mental health to act as ‘ID mental health champions’</td>
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Free e-learning
intellectual disability mental health

www.idhealtheducation.edu.au

3DN: Intellectual Disability Learning

- 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
Key Points

• People with an ID:
  – Are over-represented among offenders
  – Have higher mortality and morbidity
  – Have higher rates of mental ill health
  – May have particular health and behavioural profiles related to the cause of the ID
  – In a custodial setting may have especially high rates of stress and mental ill health
  – May not advocate for, or communicate their needs
Implications for your work

- Encouraged to learn more about ID
- Look at ways to adapt your practice
- Consider fostering the development of clearer clinical pathways in your work place
- Look for opportunities for disease prevention
- Be aware of appropriate and inappropriate treatments
- Be prepared to make reasonable adjustments to practice
  - More time
  - Modified communication
  - Modified health information
Acknowledgements/Declarations

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

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- 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