Intellectual Disability Mental Health (IDMH)

Practical Guidance for Justice Health

UNSW AUSTRALIA

Never Stand Still | Medicine | Department of Developmental Disability Neuropsychiatry

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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

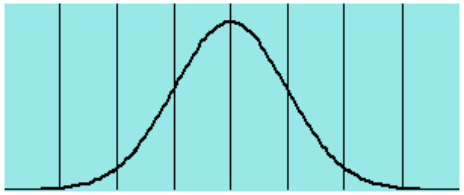
  IQ <70, ie at least 2 standard deviations below mean)

PLUS

- deficits in adaptive behaviours

AND

- onset before the age of 18



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

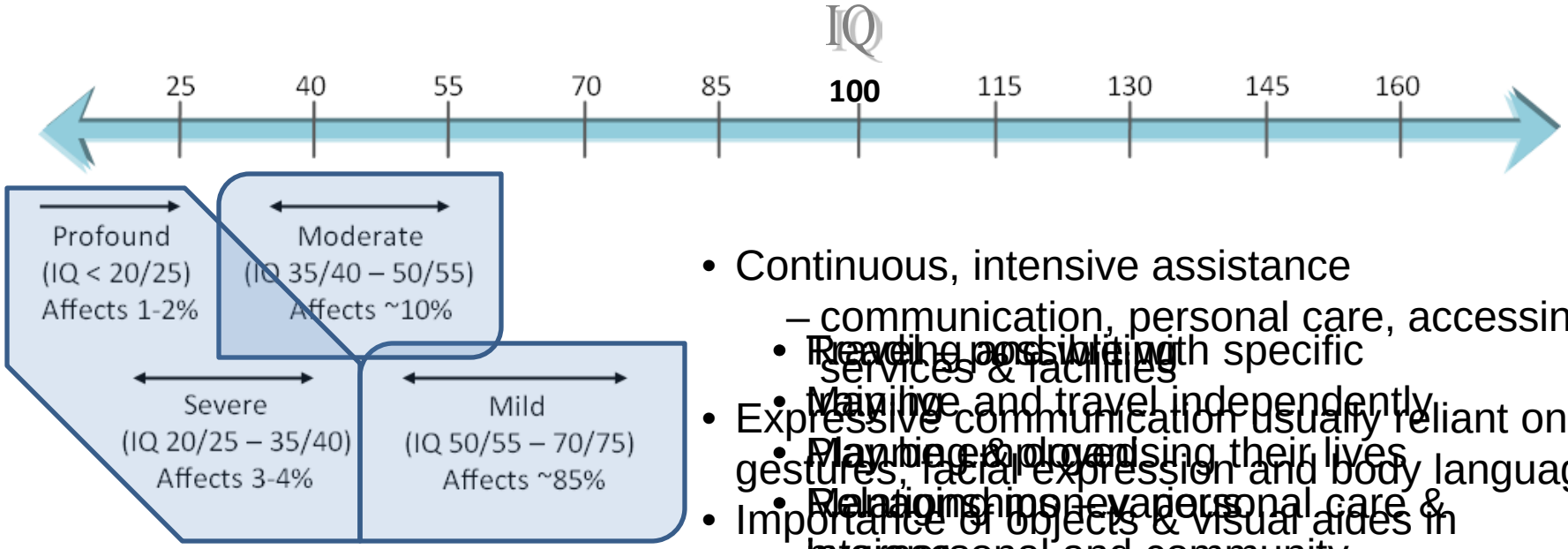
Borderline Intellectual Functioning (IQ 70-84)

- ~ 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



- Continuous, intensive assistance
  - communication, personal care, accessing services & facilities
- Expressive communication usually reliant on gestures, facial expression and body language
- Importance of objects & visual aides in communication
- Importance of relationships – recognise and form close bonds with key people[1]

1. Centre for Developmental Disability Health Victoria 2008, *Factsheet: Working with people with intellectual disabilities in healthcare settings;* http://www.cddh.monash.org/assets/documents/working-with-people-with-intellectual-disabilities-in-health-care.pdf

Causes of intellectual disability

	Conception	Gestation	Perinatal	Childhood 18
Genetic/ chromosomal disorder	*Chromosomal disorders* • Tri 21 • Fragile X • Other chromosome disorders *Syndrome disorders* • Tuberous sclerosis • Muscular dystrophies *Inborn errors of metabolism* • PKU • Lesch-Nyhan • Wilson's disease			*Degenerative disorders* • Juvenile Huntington's disease • Leukodystrophies
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]
  - Decreases with increasing disability
  - 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]

1. Bittles et al. 2002; 2. Lennox & Kerr 1997; 3. Beange, McElduff & Baker, 1995

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

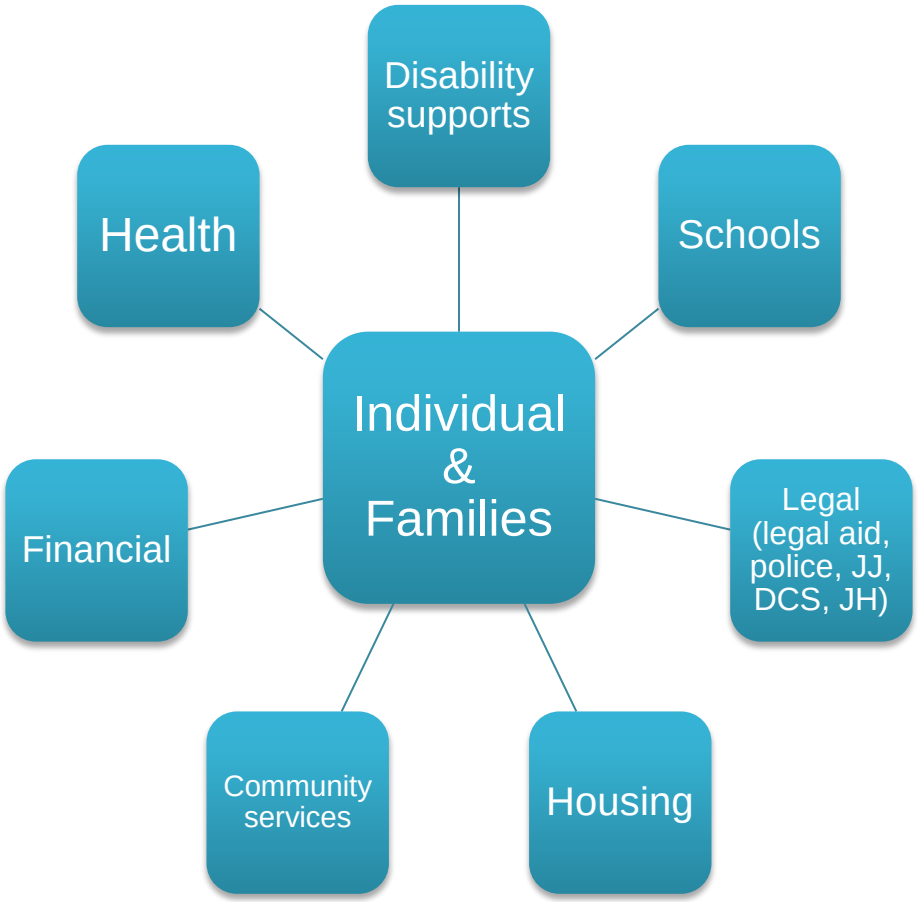
Intellectual Disability Mental Health

- 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



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 even
- Stigma
- Communication d
- Reduced s
- Absence of

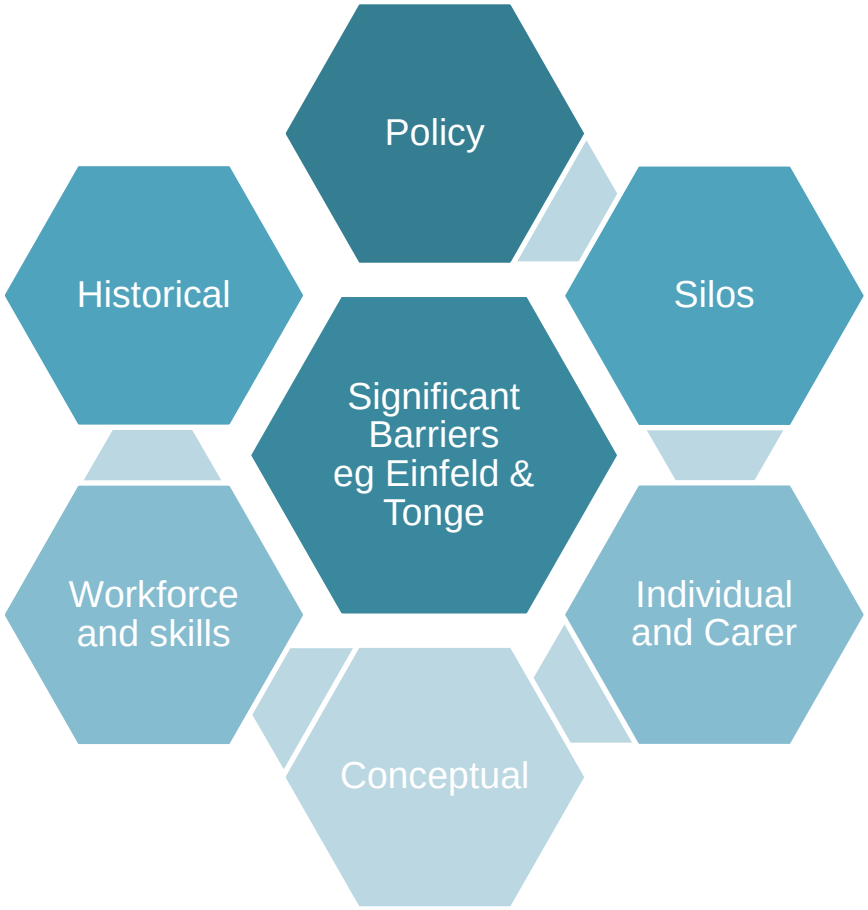
Psychological r

- Maladapt
- Feeling o
- Stress an
- Low self-
- Emotiona
- 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



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

+Model
ARTICLE IN PRESS
Rev Psiquiatr Salud Ment (Barc.). 2013;xxx(xx):xxx–xxx
ELSEVIER DOYMA
Revista de Psiquiatría y Salud Mental
www.elsevier.es/saludmental

ORIGINAL ARTICLE

Borderline Intellectual Functioning: Consensus and good practice guidelines☆,☆☆

Luis Salvador-Carulla[a,b,c], Juan Carlos García-Gutiérrez[d], Mencía Ruiz Gutiérrez-Colosía[c], Josep Artigas-Pallarès[e,f], José García Ibáñez[a,c], Joan González Pérez[g], Margarida Nadal Pla[c], Francisco Aguilera Inés[a,c], Sofia Isus[h], Josep Maria Cereza[i], Miriam Poole[j], Guillermo Portero Lazcano[k], Patricio Monzón[l], Marta Leiva[m], Mara Parellada[m], Katia García Nonell[f], Andreu Martínez i Hernández[n], Eugenia Rigau[f], Rafael Martínez-Leal[a,o,*]

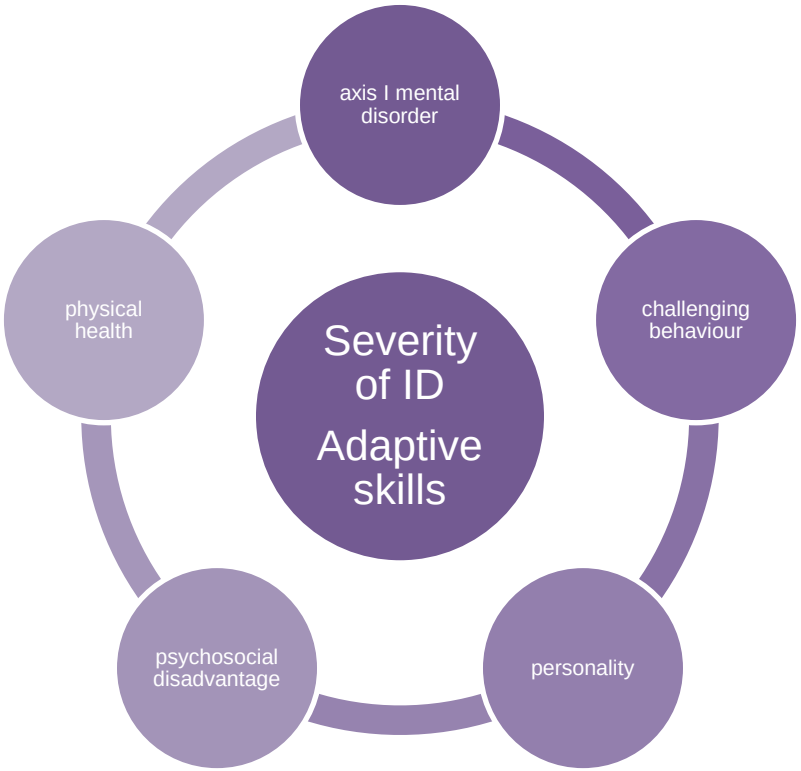
ID and Offending

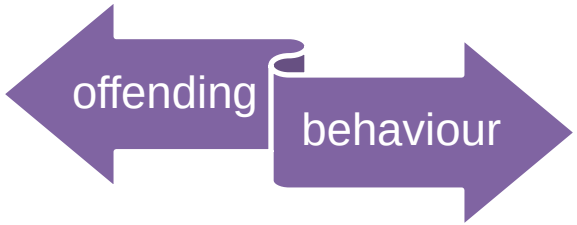
- Overrepresentation of people with ID in the CJS
- Suicide in prisoners with ID may be over-represented (Shaw et al 2003)
- A group at risk of:
  - victimisation
  - mental illness
- Deinstitutionalisation results in challenges
- Increased interest in court diversion and other non-custodial options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

How Common is ID in CJ Settings?

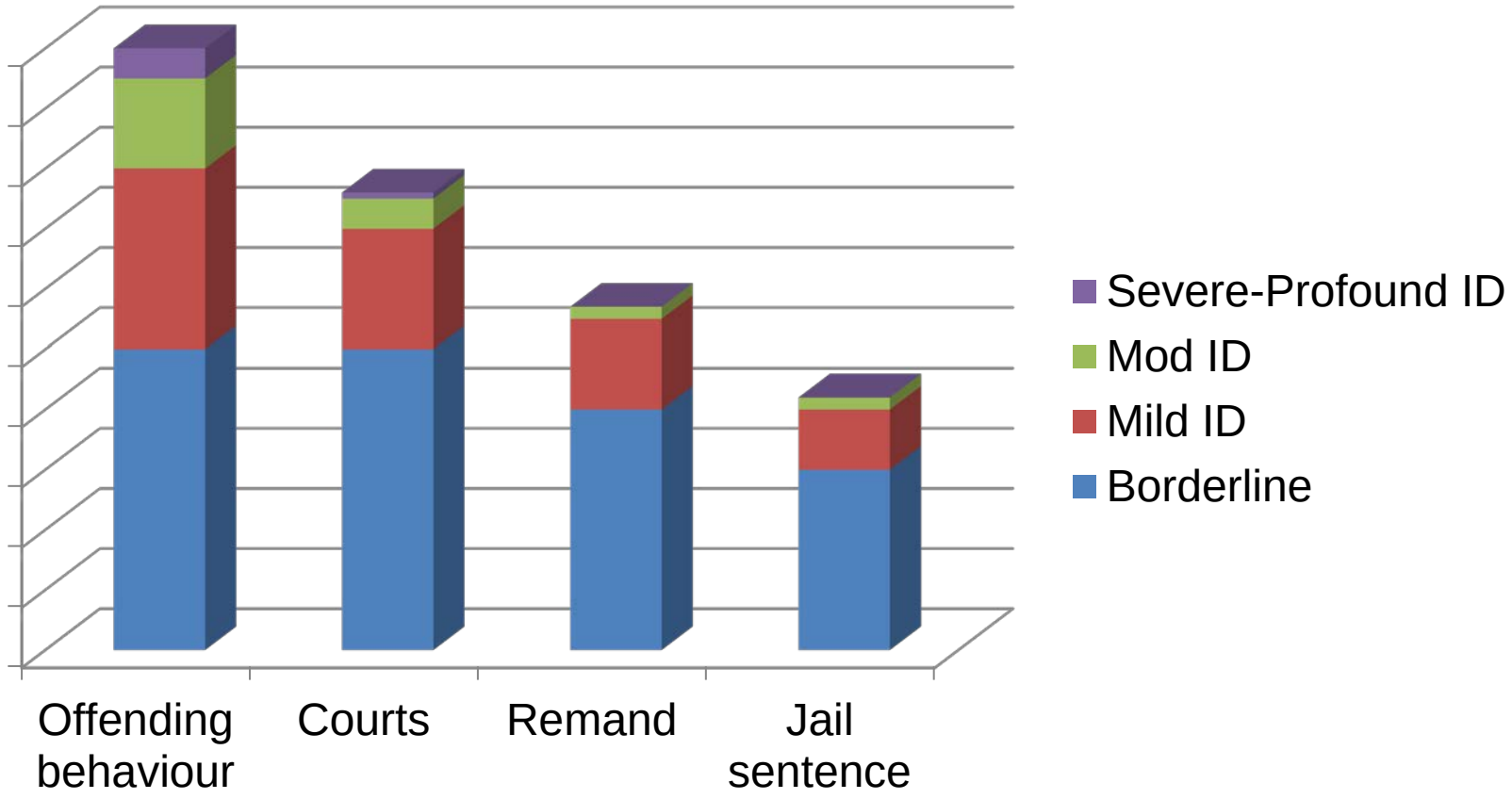
- Large variations on prevalence of ID within CJS (2-40%). (See Jones J, Int J Offender Ther Comp Criminol 2007;51:723-733; Holland JIDD 1991;17:119-126)
- 19% prevalence of ID in men in remand in Quebec (Chevrier 1993)
- 10-12% in magistrates court in NSW (Vanny et al JIDR 2009;53(3):289-297)
- Large 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





Relationship Between Level of ID, Offending behaviour and Setting



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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 psychotropic 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

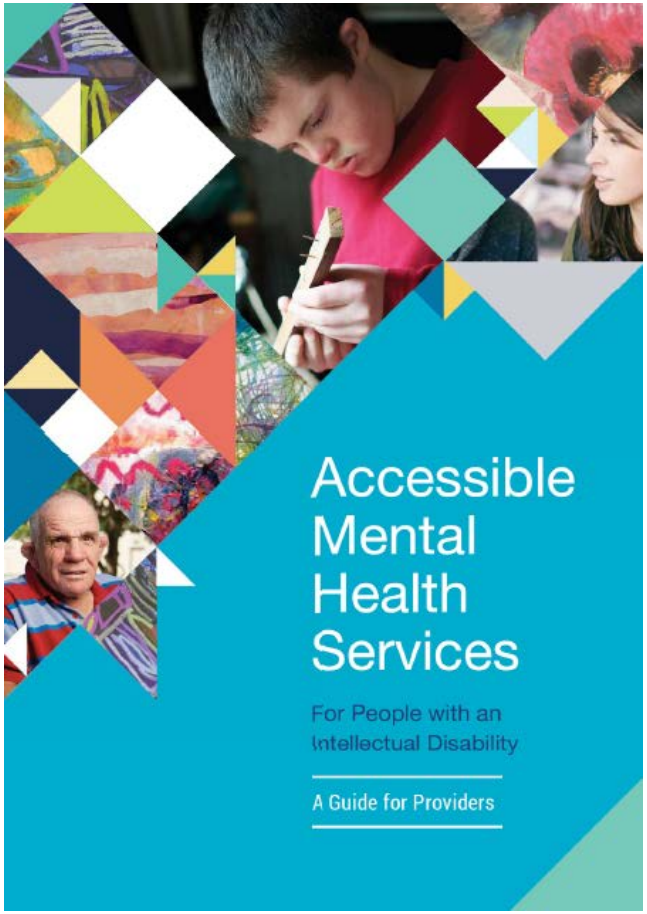
Shannon Dias, Robert S Ware, Stuart A Kinner and Nicholas G Lennox

Approach to People with an ID

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

‘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

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Key Issues for Health Professionals

Health Professional

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

Key Issues for Services Include:

For the Organisation

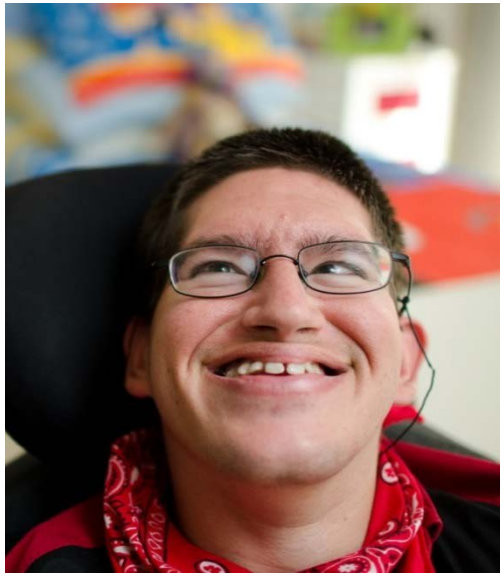
- Recognition and promotion of the rights of people with an ID to access appropriate mental health services.
- Viewing the mental health of people with an ID as core business in mental health services.
- The development of partnerships with local or regional disability services.
- An understanding of the referral processes to disability and related services, including the development of networks and partnerships with local disability services.
- The development of staff resources outlining the availability of, and access to, local or regional specialised ID health and mental health services.
- The development of identified care pathways through typical service components.
- The development of accessible information (e.g. Plain English, modified or Easy English materials) where appropriate to consumers and their families.
- Fostering staff development of skills in ID mental health through the provision of education and access to training resources
- Awareness and engagement with the academic sector.
- The development of joint initiatives between local disability and mental health services including:
  - priority referrals 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 offending behaviours;
- Identification of expertise in ID mental health to act as 'ID mental health champions'

Free e-learning
intellectual disability mental health

idmh e-Learning

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

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Key Ponts

- 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

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- 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