



Improving the Mental Health of People with an Intellectual Disability

Never Stand Still

Medicine

Department of Developmental Disability Neuropsychiatry



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Main Points

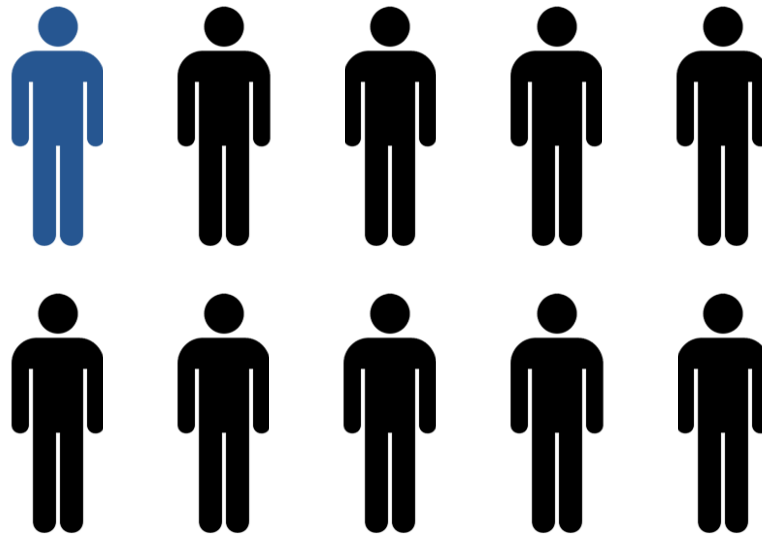
- The goal
- Mental ill health in people with an Intellectual Disability
- Barriers to access to good quality mental health care
- Improving mental health & mental health care
- Examples of recent progress and projects
- Summary
- Questions

THE HIGHEST ATTAINABLE STANDARD OF MENTAL HEALTH AND WELLBEING FOR PEOPLE WITH AN INTELLECTUAL DISABILITY

- Talk to:
 - consumers
 - family carers
 - health advocates
 - disability sector
- Examine:
 - available prevalence data
 - skills and training of mental health professional
 - mental health services
 - mental health policy

How Common are Mental Health Problems? General Population

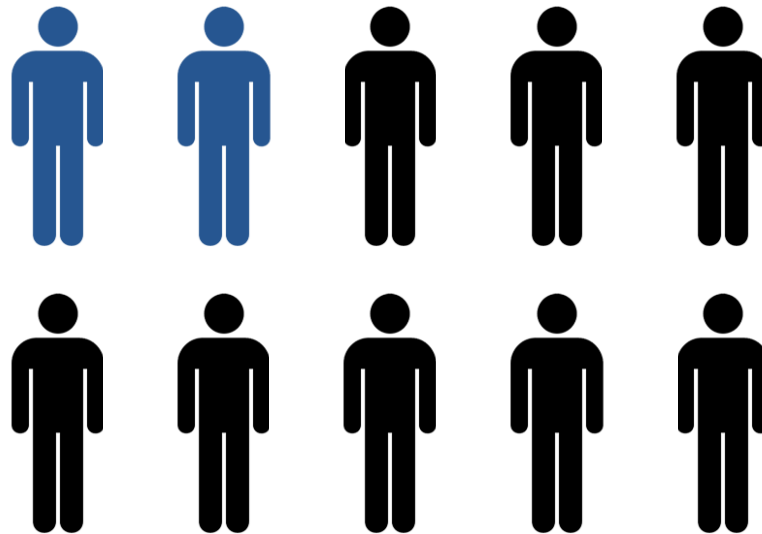
- About 1 in 10 people in a month (NB survey excluded people with an ID)



2007 National Survey of Mental Health and Wellbeing

How Common are Mental Health Problems? General Population

- About 2 in 10 people in a year

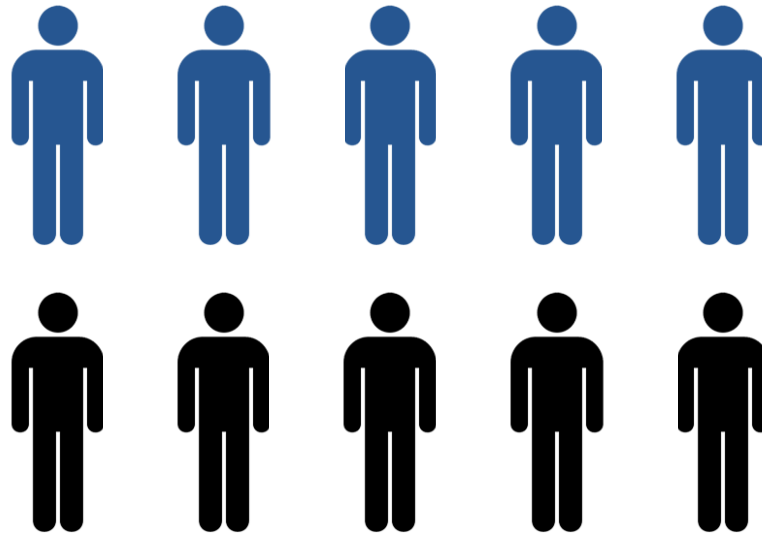


2007 National Survey of Mental Health and Wellbeing

How Common are Mental Health Problems?

For people with ID

- About 4 or 5 out of every 10 people in a year

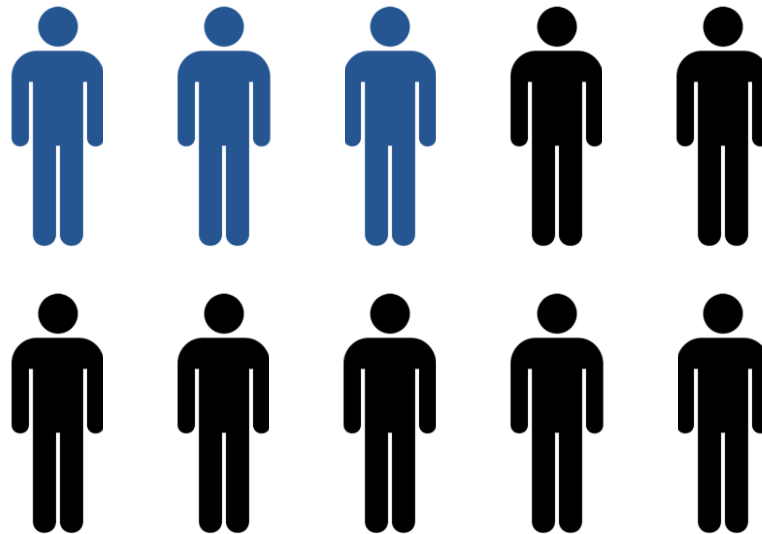


Cooper et. al., 2007

How Common are Mental Health Problems?

For carers

- About 3 out of every 10 people in a year



Savage and Bailey, 2004

Mental Health of People with an ID

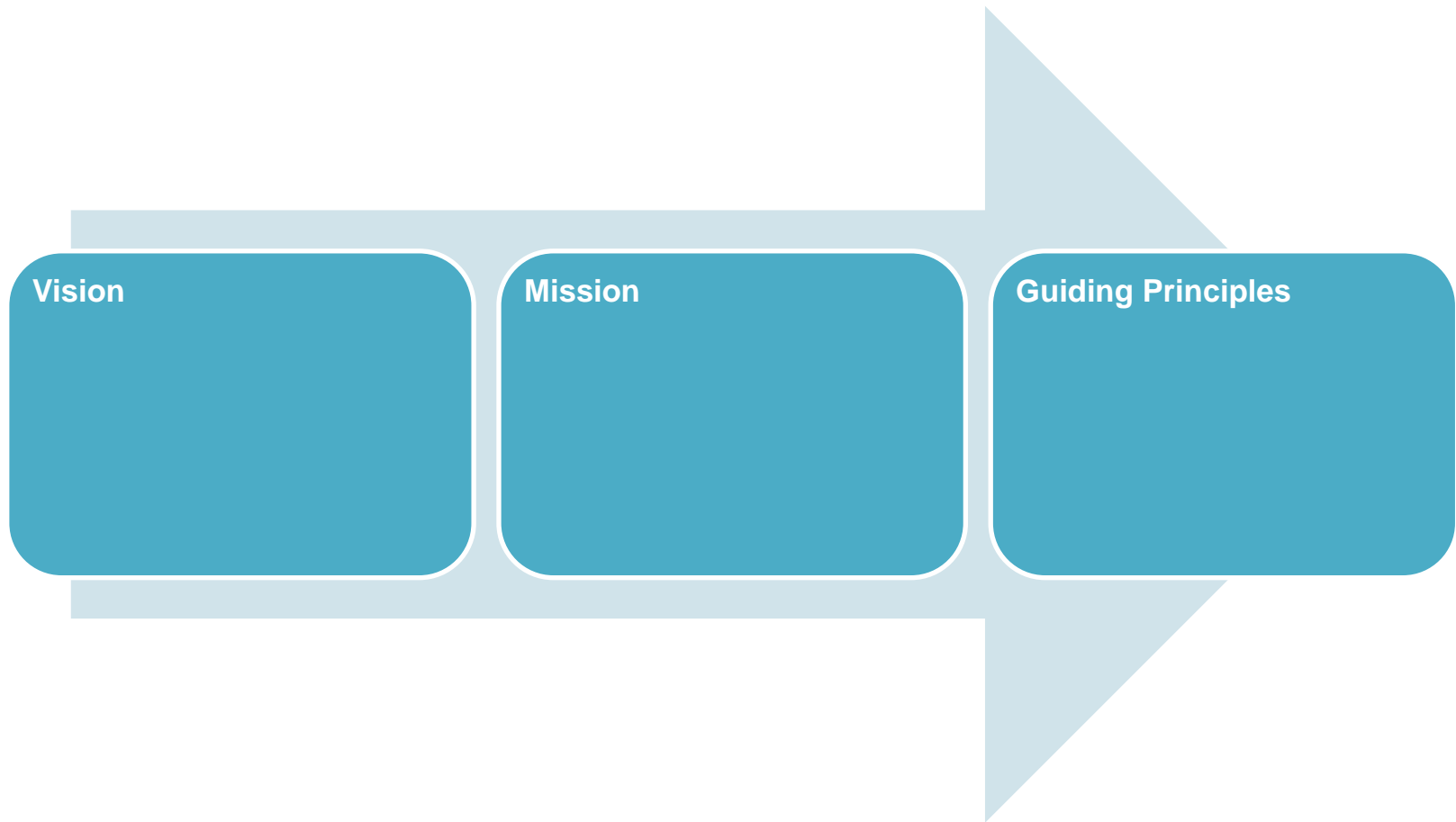
- People with an intellectual disability experience an over-representation of mental disorders
 - Conservative estimates for adults/children with ID 2.5/3-4x
- At any one time, an estimated 20-40% of people with an ID will be experiencing a mental disorder of some kind.
- Access to mental health supports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



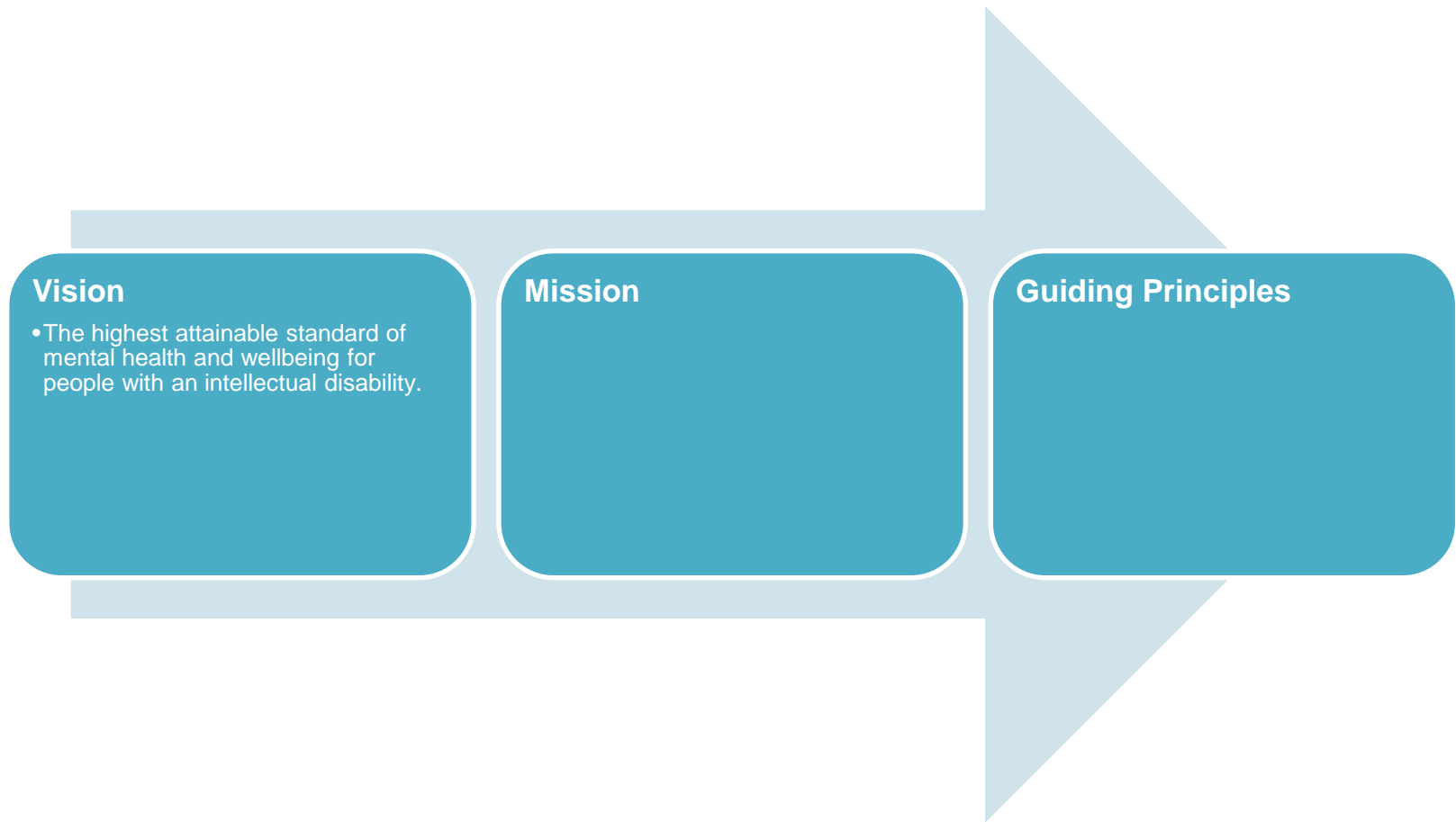
ID Mental Health across the Lifespan

- 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.

Approach



Approach



Approach

Vision

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

Mission

- To improve mental practice and policy for people with an intellectual disability.

Guiding Principles

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- Innovation in health services
- Collaboration

Access to MH Services and Supports



Vulnerabilities to Mental Disorder

Social risk factors

- Social isolation
- Social adversity
- Adverse life events
- Stigma
- Communication difficulties
- Reduced social support
- Absence of family

Biological risk factors

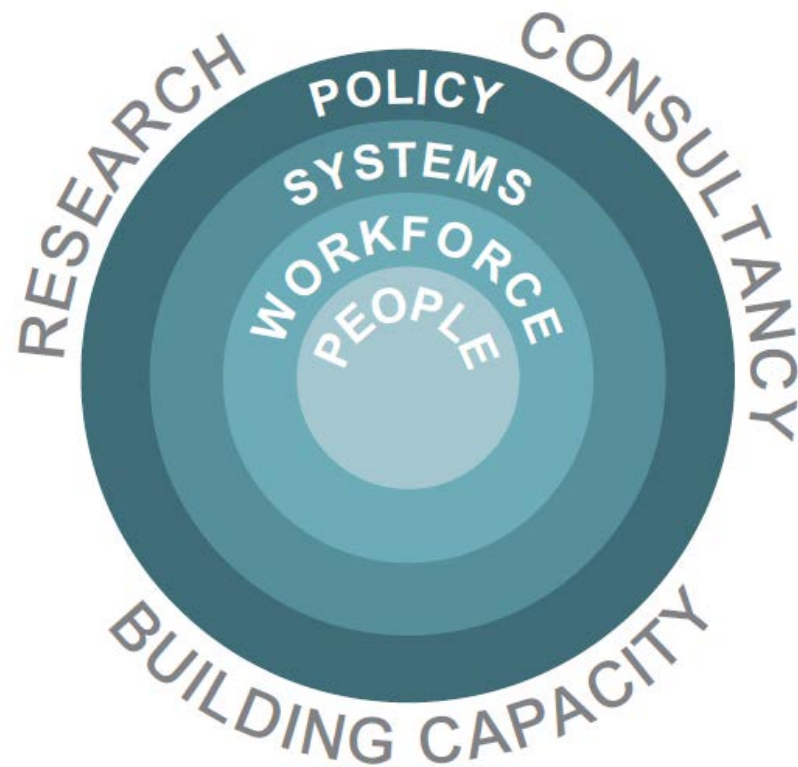
- Physical inactivity
- Poor diet
- Multiple health conditions
- Polypharmacy
- Epilepsy
- Head injuries
- Family history of mental disorder
- Genetic anomalies – eg Velocardiofacial syndrome is associated with higher rates of mental disorder, particularly schizophrenia

Psychological risk factors

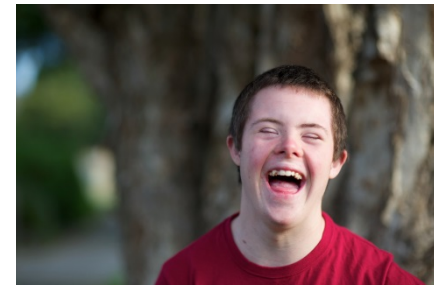
- Maladaptive coping
- Feeling of helplessness
- Stress and anxiety
- Low self-esteem
- Emotional lability
- Capacity for self-harm

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



People



Macro Strategies

- Improved pre, peri & postnatal care
- Improved access to housing, education, employment
- Strengthening community networks

Enhancing Resilience

- Early intervention in developmental lags
- Childhood disorders
- Reducing neglect and abuse
- Enhancing social skills and peer relationships
- Strengthening families
- Work place participation and interventions
- Mental and physical activity across the lifespan
- Addressing medical risk factors for mental ill health

People



- The experience of mental ill health
- The experience of mental health care
- Barriers and enablers to access for the person and their carers
- Consumer, carer and advocate perspectives on:
 - priorities for reform and service development
 - Attributes expected of the workforce
- Data
 - Epidemiology
 - Outcomes

“the person is the expert in their own experience”

Mental Health professional, disability service

Workforce

“Respectful interactions are not only mutually rewarding but assist the process of recovery.”

Mental health professional, ID mental health service

- Understanding training needs
- Access to appropriate training
- Competencies
- Professional development
- Professional bodies
- Champions

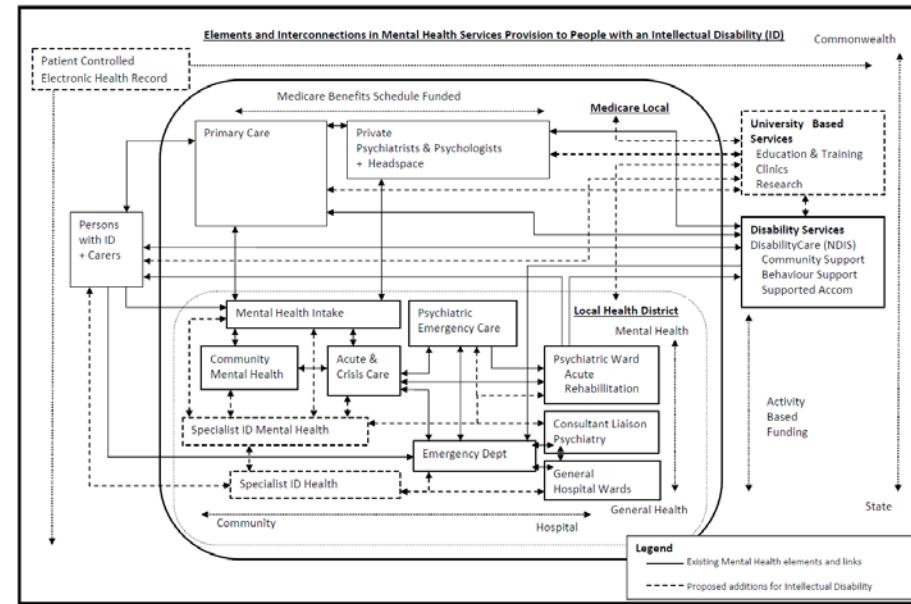


Systems

"It took many years to get the help that my son needed. He was misdiagnosed with autistic disorder when he was actually psychotic. Regrettably, it was only after he had contact with the law that he was provided with the assessment and management he needed."

Alan, parent and carer

- Clinical
 - Consumer health information
 - Diagnostic tools
 - Clinical pathways
- Service Mapping
- Service Development
 - Tiered
 - Joint service planning
 - Flexible boundaries
- Outcomes
 - Measures of effectiveness



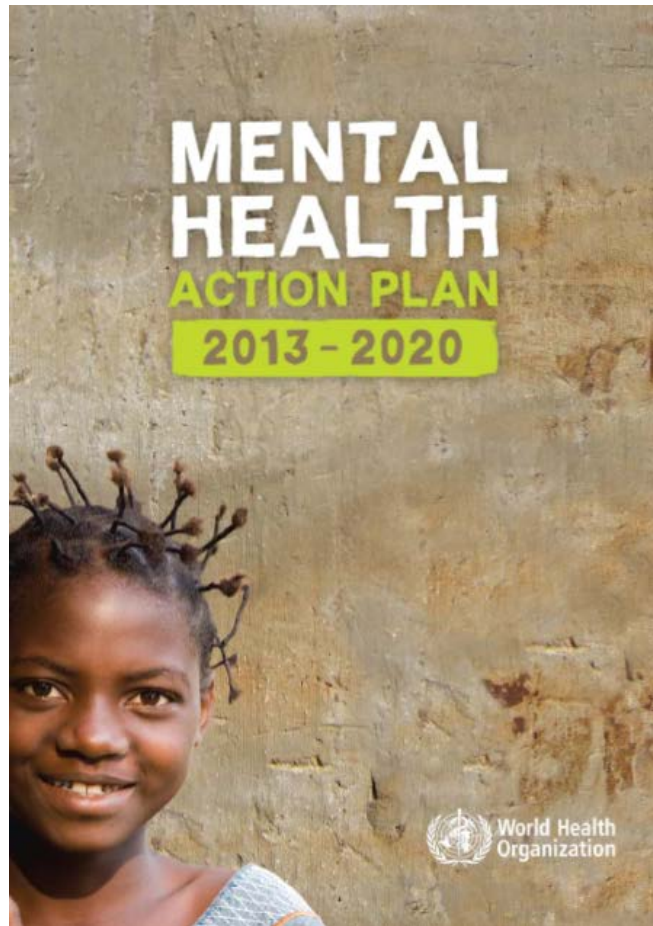
Policy

- Proactive approach
- Universal inclusion of people with ID in all mainstream mental health policy development
- Adequate consultation with key stakeholders

“Troy aged 45, has a mild intellectual disability and autistic disorder. He lives independently and enjoys fishing, going on holidays, and spending time with his father. He developed depression, and became isolated from his community and family. He came close to disengaging from services and was at risk of homelessness. A [Memorandum of Understanding](#) between mental health and disability services guided collaboration between service providers. Troy was provided with flexible service delivery and holistic support from staff who respected and responded to his needs. He has made significant gains in health, is engaged in decision making and is a valued member of his local community.”

Mental Health Professional, mental health service

WHO Mental Health Action Plan



Objectives

1. Strengthen effective leadership and governance for mental health
2. To provide comprehensive, integrated and responsive mental health and social care services in community-based settings
3. To implement strategies for promotion and prevention in mental health
4. To strengthen information systems, evidence and research for mental health

National Round Table in ID & Mental Health



NATIONAL ROUNDTABLE ON
THE MENTAL HEALTH OF
PEOPLE WITH INTELLECTUAL DISABILITY

COMMUNIQUÉ

Great Hall, University House,
Australian National University,

Wednesday 22nd May 2013

<http://www.nswcid.org.au/images/communique.pdf>

- 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

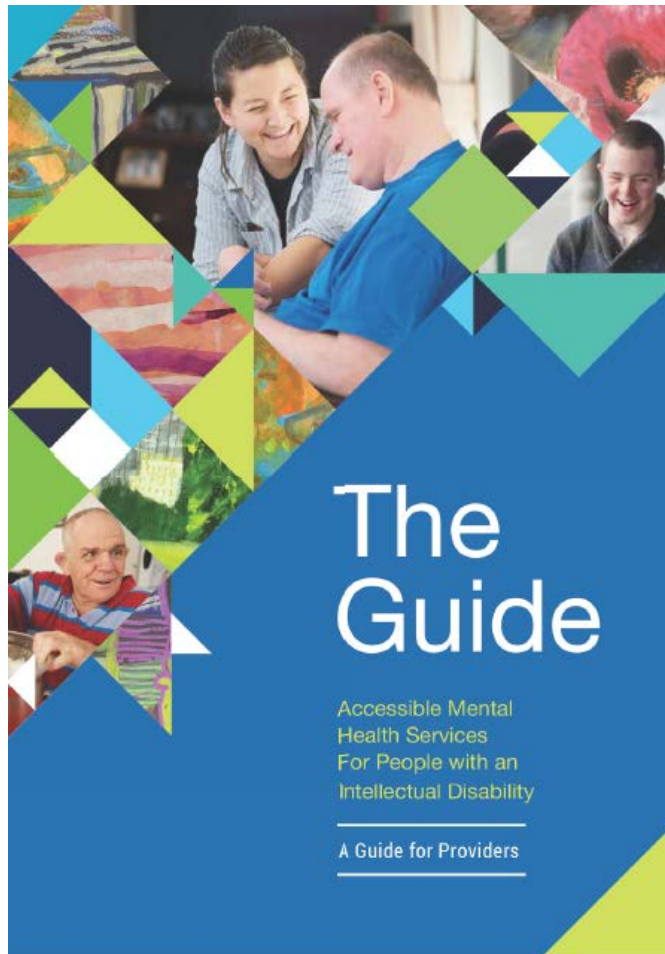


Approach to People with an ID

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

Further enhancement Individual + Organisation

- All mental health professionals
- Primary care
- Public mental health services
- Private mental health services
- Specialist ID health and Mental Health services

Key Issues for Health Professionals

Health Professional

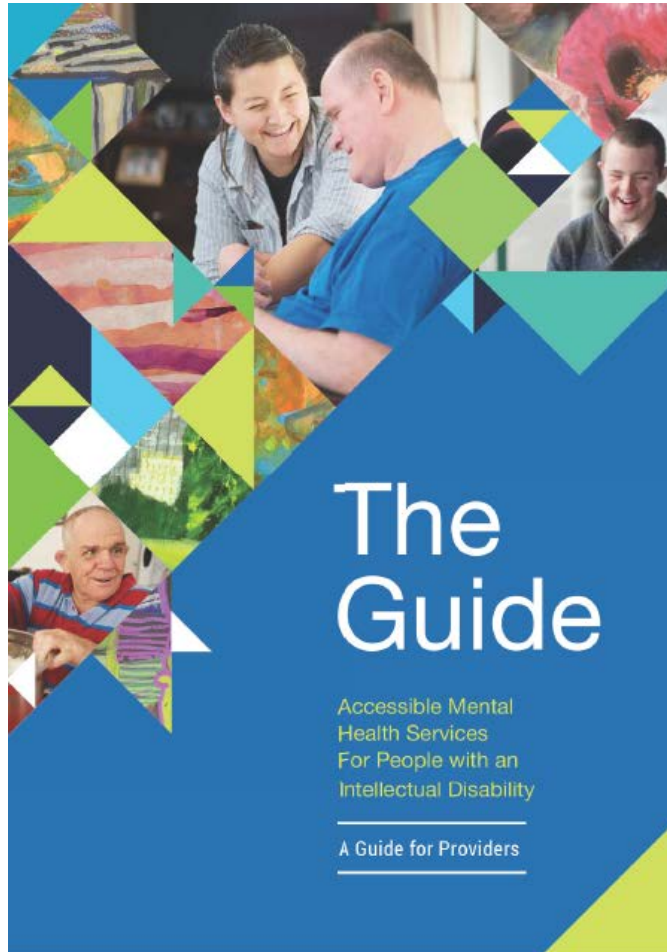
- Competent mental health assessments.
- Appropriate management plans.
- Timely reviews.
- Regular review of psychotropic medications and monitoring any potential side-effects.
- Identification and familiarity with care pathways
- Partnerships with local or regional disability services.
- Availability 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'

‘Accessible Mental Health Services for People with ID: A Guide for Providers’



Release

- *Early 2014*

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

Challenges

- NDIS
- People with complex disabilities
- People in contact with the criminal justice system
- State-based Disability services
- Mental health reforms

Key Points

- People with an ID:
 - Have higher rates of mental ill health
 - Experience multiple barriers to effective and high quality mental health care
- Complex reasons: person, workforce, systems and policy levels

Implications

- A complex problem 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)
- Continued lobbying and reform is required

THE HIGHEST ATTAINABLE STANDARD
OF MENTAL HEALTH AND WELLBEING
FOR PEOPLE WITH AN INTELLECTUAL
DISABILITY



Acknowledgements/Declarations

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

