NSW Carer Support Program: Developments in Intellectual Disability Mental Health

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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
• Discussion: your perspective
• Questions
The Goal

- THE HIGHEST ATTAINABLE STANDARD OF MENTAL HEALTH AND WELLBEING FOR PEOPLE WITH AN INTELLECTUAL DISABILITY
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.
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 engagement
- Absence of meaningful social interactions

**Psychological risk factors**
- Maladaptations
- Feeling of isolation
- Stress and anxiety
- Low self-esteem
- Emotional dysregulation
- Capacity limitations

**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
Poorer access to treatments

• Low rate of treatment & often unknown to mental health services
  – Only 10% of adults with ID and psychopathology received mental health interventions across a 14 year period (Einfeld et al., 2006)
  – cf. 34.9% of people with a mental disorder accessed mental health services within a 12 month period (Slade et al., 2009)

• Reasons?
  – Families & care staff untrained in mental health, unable to recognise indicators
  – Inadequate mental health professional training in ID
  – Diagnostic difficulties
  – Until recently there has been little research on the use of psychological therapies other than behavioural treatments for people with ID (Emerson & Holland, 1997)
Access to MH Services and Supports

- Policy
- Silos
- Significant Barriers
- Conceptual
- Individual and Carer
- Workforce and skills
- Historical
The Carer Perspective: Clinical

- High levels of stress and burden
- Often lifelong role
- Impacts at so many levels
- A journey with a specific life cycle
- In the health context
  - Clash of cultures, values and attitudes
  - Apprehension, lack of care pathways and skills
Carer Involvement in Research, Education and Services Development

- We (researchers, educators and service developers) need education
- Improvements
- Inclusive approaches being adopted
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
• Human rights
• Equity in mental health care
• Person centred approach
• Promoting independence
• Recovery-oriented practice
• Evidence based
• Innovation in health services
• Collaboration
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.
Exemplars of 3DN’s Capacity Building Work

• Accessible Mental Health Services for People with ID: A Guide for Providers (‘The Guide’)
• State-wide survey of MH staff attitudes, confidence and learning needs in ID
• Education for
  – Medical students, specialist trainees
  – mental health workers
  – disability workers
  – carers and consumers
• Competencies in IDMH for the NSW Mental Health Workforce
  – Carer and consumer consultation process
• 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 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
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
The Guide
Accessible Mental Health Services for People with an Intellectual Disability
A Guide for Providers

Available online
3dn.unsw.edu.au
Available online
3dn.unsw.edu.au
The Guide: What is it?

- A national framework of understanding and action for mental health professionals and service providers.
- Documents the understanding of ID mental health, current national and international practices.
- Provides an overview of ID mental health, why accessible services are important, the principles that should guide service delivery, practical strategies for inclusive and accessible services, and the implications for the service system.
- Facilitates and encourages incremental steps to adjustments to practice, accessible service and knowledge and capacity building.
Accessible Mental Health Services for People with ID: A Guide for Providers (‘The Guide’)

Methodology

• Funding
• Core Reference Group formation
• Background research and collation
• Draft sections for CRG consultation
• Focus group consultation
• Second Draft and circulation
• Final Draft
• Publication
• Launch
• Follow-up actions
The Vision

Accessible mental health services for people with an intellectual disability.
Core Reference Group

The Core Reference Group (CRG) was consulted throughout the development of The Guide.

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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 emphasize 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 disorder. The mental health support needs of people with a mild ID can often be met within mainstream mental health services. However, people with communication deficits, 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 is a complex and challenging task. Key national and international initiatives and policies are necessary to ensure that mental health services are accessible and effective for all 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 by 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.

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 recognize 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.

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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 as can developmental 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 manifest as problematic behaviour. 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 ill-health 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 1 - 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 (UNCRPD) (see p. 6), in which Australia is a signatory, commits all levels of government in Australia to ensuring the right of people with disabilities to 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.

INCLUSION

People with an ID have the right to full participation in all aspects of community life. People with an ID should be able 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 the 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.

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 age and capacity. While the person is the locus, 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.

*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 canceling 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.

“...expertise in mental health is an important component of effective case management.”
- Consumer, disability service

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(s), 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(s);
  - 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.


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

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

The Developmental Behaviour Checklist


This resource provides an overview of the various measures used to assess mental health concerns in adults with an ID.

Diagnostic Manual - Intellectual Disability (DM-ID): A Textbook of Diagnosis of Mental Disorders in Persons with Intellectual Disability

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


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

www.copsy.ac.uk/usefulresources/publications/books/ccpp/16901242994.aspx

The CANDID has been developed and tested by a multidisciplinary team at 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 is a suite of instruments for the assessment of behavioural and emotional problems of children, adolescents and adults with developmental and intellectual disabilities.

www.dmid.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.

www.rcpsych.ac.uk/publications/collergereports/op/ep46.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
Challenges and Opportunities

• Mental health reforms
  – NSW Mental Health Commission
    o Carer and consumer engagement strategy
  – National Mental Health Commission

• NDIS

• Disability services

• Specific Groups
  – People with complex disabilities
  – People in contact with the criminal justice system
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
• Capacity building is occurring but is a slow process
• Need to push this area within mental health reform
• Key role for consumer and carer input
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
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• Australian Government Department of Health and Ageing
• Australian Research Council (ARC)
• National Health and Medical Research Council (NHMRC)
• NSW Institute of Psychiatry
• Autism CRC