Developmental Disabilities, Challenging Behaviour and Mental Health: Advancing Policy

Initiatives at the intersection with Mental Health

Julian Trollor
Department of Developmental Disability Neuropsychiatry
School of Psychiatry, UNSW
j.trollor@unsw.edu.au
Disclosures
Disclosures
http://mobro.co/unsw3dn

Our Motivation

Team 3DN want to raise awareness of the disproportionate burden of mental health issues experienced by men with an intellectual disability, for whom services and supports are limited. For more information see http://3dn.unsw.edu.au/ Please support us as we turn ugly for a good cause.
Behaviours (and responses)

- Socio-political & cultural context
- Theoretical & ethical framework
- Wider community attitudes and approach
- Models of support
- Immediate environment
- Behaviours

- Biological
- Psychological
- Social
Effective Services and Supports

Policy

Individual and Carer

Barriers & Enablers

Historical

Workforce and Skills

Silos

Conceptual

Individual and Carer

Barriers & Enablers

Historical

Silos

Conceptual

Individual and Carer

Barriers & Enablers

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Conceptual

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Conceptual

Individual and Carer

Barriers & Enablers

Historical

Silos

Conceptual
Key Ideas

• Current policies and service models are confused about where challenging behaviour and psychological supports fit

• There are mounting social and political imperatives for the development of shared responsibility for mental ill health and challenging behaviour in people with an intellectual disability

• Data on the intersection between disability, behaviour, mental health (and health) supports the need for a mental health workforce with skills in assessing and managing challenging behaviour and its intersection with mental ill-health

• Some developments and resources to assist
Supports for People with Intellectual Disability and Challenging Behaviour

Person Centred supports
Enabling participation
Supports for People with Intellectual Disability and Challenging Behaviour

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Person Centred supports
Enabling participation
Current Practice in Australia

- Funding, practice and monitoring of quality and safety for behaviour support lies outside health/mental health
- Health/mental health does not view this as an area of responsibility
- There is limited capacity for cross sector collaboration and multidisciplinary clinical frameworks
- Review of restrictive practices sit for challenging behaviour lies outside mental health
- Yet, both disability and mental health services acknowledge importance of:
  - each area to the overall well being of the person
  - cross sector collaboration
  - the multidisciplinary approach as best practice
POLICY
Relevant Australian Policy

- State based policies eg ADHC’s Behaviour Support: Policy and Practice Manual, recognises mental health as a critical area of assessment for behaviour support
  

- National Framework for Reducing and Eliminating the Use of Restrictive Practices in the Disability Service Sector
  
  
  - Guiding Principles: 6. Collaboration: commitment to developing and maintaining stronger relationships across the health, allied health, aged care and disability sectors, including between physicians, nurses, mental and other health professionals, and disability services staff to ensure a multidisciplinary approach to the monitoring, use and reduction of restrictive practices.
Relevant Australian Policy

- The National Standards for Mental Health Services (2010)
  - Services should be diversity responsive, including to people with an ID (Standard 4), ……ensure equity of access.
  - Services are called on to consider the needs of carers, including specifically the carers of people with ID (Standard 7).

- National Practice Standards for the mental health workforce 2013
  - Mention of values, attitudes and workforce skills for people with a disability
Relevant Australian Policy

• A national framework for recovery-oriented mental health services 2014
  – “Rates of mental illness are high for…. people with intellectual disability, autism spectrum disorders”
  – “Working with people who have experienced considerable adversity…..intellectual disability”

• Roadmap for National mental health reform 2012-2022
  – Vision: well integrated …. services – including in the fields of health, ………, disability, justice ……that work closely …….., and are set up to be responsive ……..ensuring ……..multiple service pathways, with ‘no wrong door’ …..
At Face Value

• Our policies within the disability and mental health sectors
  – say some good things
  – talk about collaborative frameworks
  – but don’t deliver significant service system changes to allow effective delivery
Progress and Opportunities in Policy and Practice

• Australian Law Reform Commission: *Equality, Capacity and Disability in Commonwealth Laws* (May 2014)
  

• National Seclusion and Restraint Project
  

• NDIS
  
Mental Health and Challenging Behaviour in People with an ID

• People with an intellectual disability experience:
  – an over-representation of mental disorders
  – an over-representation of challenging behaviours

• At any one time,
  • 20-40% experience a mental disorder
  • 10-20% experience challenging behaviour

• Access to mental health supports and behavioural supports is limited, especially for high complexity

• High impact for people with ID, families and carers
Conceptual Relationships between Challenging Behaviour and Mental Ill Health

• Unrelated, ie no correlation
• If there is a correlation, then:
  – There is no connection between challenging behaviour and mental illness; the correlation is coincidental
  – There is no connection between challenging behaviour and mental illness; the correlation is artefactual; eg may share diagnostic constructs or symptoms, so that facets of CB may be counted toward diagnostic criteria for mental disorders or vice versa
  – Challenging behaviour, or its treatment, could cause mental illness;
  – Mental Illness, or its treatment, could cause challenging behaviour
  – Both challenging behaviour and mental illness are consequences of a common cause, but do not cause each other;
## Association between Challenging Behaviour and Mental Disorder

<table>
<thead>
<tr>
<th>Reference</th>
<th>Specific Findings</th>
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</table>
| Lowry & Sovner 1992           | 2 patients with severe ID and rapid cycling bipolar:  
- Depressive features associated with SIB  
- Manic features associated with aggression |
| Martson et al 1997            | Depression associated with:  
- Screaming, aggression, SIB (Severe ID)  
- Tearfulness, weight loss, lost confidence (Mild ID) |
| Moss et al 2000               | Depression and challenging behaviours most marked association                                                                                  |
| Tsiouris, Cohen, Patti and Korosh, 2003 | Addressing psychiatric conditions associated with reduced self-injury                                                                          |
| Holden & Gitlesen 2003        | Both anxiety and psychosis most markedly associated with challenging behaviours, but *not* mania                                                |
## Association between Challenging Behaviour and Mental Disorder

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<tr>
<td>Rojahn et al 2004</td>
<td>SIB, Aggression <em>not</em> associated with Depression</td>
</tr>
<tr>
<td>Rojahn, Matson, Naglieri and Mayville, 2004</td>
<td>Presence of challenging behaviours associated with overall higher psychopathology, but specific behaviours <em>not</em> associated with specific disorders</td>
</tr>
<tr>
<td>Hemmings et al 2006</td>
<td>Self-injury and aggression related with affective disorders</td>
</tr>
<tr>
<td>Myrbakk &amp; von Tetzchner 2007</td>
<td>Screaming, tantrums, aggression &amp; SIB associated with depression</td>
</tr>
<tr>
<td>Hurley 2008</td>
<td>Aggression, tantrums, self-stimulation, underactivity, rituals and impulsivity associated with depression</td>
</tr>
<tr>
<td>Reference</td>
<td>Association?</td>
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</table>
| Martson et al 1997              | ✓            | Severe ID: Screaming, aggression, SIB  
Mild ID: tearfulness, weight loss, lost confidence | ✓ In symptom presentation       |
| Moss et al 2000                 | ✓            | Severe challenging behaviour                                                        |                                  |
| Ross & Oliver 2002              | ✓ / ×        | All challenging behaviour                                                           |                                  |
| Tsiouris et al 2003             | ×            | All challenging behaviour                                                           | ✓ In symptom presentation       |
| Rojahn et al 2004               | ×            | SIB, Aggression                                                                    |                                  |
| Hemmings et al 2006             | ✓            | SIB, Aggression                                                                    |                                  |
| Myrbakk & von Tetzchner 2007    | ✓            | Screaming, Tantrums, Aggression, SIB                                                |                                  |
| Hurley 2008                     | ✓            | Aggression, Tantrums, self-stimulation, SIB, Underactivity, Rituals, Impulsivity     |                                  |
The Purported Association Between Depression, Aggression, and Self-Injury in People With Intellectual Disability: A Critical Review of the Literature

Louise Ellen Davies and Chris Oliver

• Questions the association between depression and specific challenging behaviours

• Major methodological problems
  – Small numbers
  – Reliance on response to treatments
  – Different definitions of challenging behaviour/depression
  – Dubious statistical approaches

• Major findings
  – About 1/3 studies showed an association; 1/3 studies failed to show an association; 1/3 studies inconclusive
Association between Challenging Behaviour and Physical Health

- Increased rates of morbidity in people with ID [1]
- Co-morbid conditions may not be diagnosed or well managed [2, 3]
- Lower socio-economic status increases risk of both physical and mental ill-health [4]
- In people with ID who have difficulty communicating, physical health problems have been found to be associated with changes in behaviour [6, 7, 8]
- Physical symptoms, chronic disease history, and lengthy hospitalisations are associated with current and future psychopathology [5]

INITIATIVES
Capacity Building in Intellectual Disability/Mental Health/Complex Behaviour

- 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

“Ensuring planners developing participant plans have skills in intellectual disability mental health and challenging behaviour.”
Further National Developments in ID Mental Health

Now on NSW CID’s Website

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

www.idhealtheducation.edu.au
Attitudes and beliefs
• Within this area it is critical that mental health professionals adopt and apply the following attitudes and beliefs in their clinical practice. They include:
  – Working with others to address challenging behaviour (also known as behaviours of concern).

Assessment – Challenging Behaviour
• 8.9 Demonstrates the ability to assess the relative contribution of mental health, physical health, environment, communication, and skills to behaviours.
• 8.10 Collaborates with disability services, and other relevant stakeholders to provide a comprehensive assessment of challenging behaviour.

For project status:
The Guide

Accessible Mental Health Services for People with an Intellectual Disability

A Guide for Providers
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.
The Guide

• Specifies specific roles and responsibilities of the individual and the organisation
  – Primary health care
  – Public mental health
  – Private mental health
  – Specialist ID health
• At 2 levels:
  – Fundamental or basic roles and responsibilities
  – Further enhancement of practice and services
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.

<table>
<thead>
<tr>
<th>CRG Member</th>
<th>Position</th>
<th>Organisation / Professional Association and Interest Group</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ms Andrea Ching</td>
<td>Project Manager The Guide</td>
<td>Department of Developmental Disability Neuropsychiatry, School of Psychiatry, University of New South Wales</td>
</tr>
<tr>
<td>Dr Catherine Franklin</td>
<td>Senior Lecturer and Consultant Psychologist</td>
<td>Queensland Centre for Intellectual and Developmental Disability at the University of Queensland</td>
</tr>
<tr>
<td>Dr Linda Cockburn</td>
<td>President</td>
<td>Professional Association of Nurses in Developmental Disability Australia</td>
</tr>
<tr>
<td>Dr Nick Haglindo</td>
<td>Psychologist and Committee member</td>
<td>Australian Society for Intellectual Disability</td>
</tr>
<tr>
<td>Prof Nick Lennox</td>
<td>President</td>
<td>Australian Association of Developmental Disability Medicine</td>
</tr>
<tr>
<td>A/Prof Keith McVitty</td>
<td>Convener, Special Interest Group on People with Intellectual and Other Developmental Disabilities</td>
<td>Australian Psychological Society</td>
</tr>
<tr>
<td>Mr Andrew Piddington</td>
<td>Aboriginal Mental Health Nurse Practitioner</td>
<td>Australian College of Nurses Health Nurses</td>
</tr>
<tr>
<td>Mr Jim Simpson</td>
<td>Senior Advocate</td>
<td>NSW Council of Intellectual Disability</td>
</tr>
<tr>
<td>Dr Jennifer Torr</td>
<td>Chair, Special Interest Group in the Psychiatry of Intellectual and Developmental Disabilities</td>
<td>Royal Australian and New Zealand College of Psychiatrists</td>
</tr>
<tr>
<td>A/Prof Julian Trolor</td>
<td>Chair, Core Reference Group</td>
<td>Chair Intellectual Disability Mental Health, School of Psychiatry, University of New South Wales</td>
</tr>
</tbody>
</table>
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 emphasise 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 disorders. 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 in Australia lags behind internationally accepted practice. The experience of family, carers and consumers is that mainstream mental health services do not readily accommodate the needs of people with an ID. Workforce capacity in this area is lacking, and mental health professionals have limited training, education and expertise in ID mental health. While preventative mental health programs are broadly aimed at all Australians, programs that specifically assist people with an ID are largely non-existent.

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 recognise 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.

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 of 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 fair or affordable mental health care.
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 areas 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 may present 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 7 – Training and Education p. 57).

“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 (CRPD) (see p. 66), to which Australia is a signatory, commits all levels of government in Australia to ensuring the right of people with disability 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 specialist 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 service staff. This includes their willingness to engage and actively include family members and support staff in the planning, implementation and review of treatment programmes.

PERSON-CENTRED APPROACH

A person-centred approach to mental health maximizes 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, keeping with their age and capacity. While the person is the focus, 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 recognize the autonomy of individuals with an ID whilst acknowledging their age and capacity, and work in a manner that maximizes 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 those 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.

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"Expertise in mental health is an important component of effective case management."

- Consumer, disability service

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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 recognize 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 carer(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 carer(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 utilizing 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.


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

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

http://ddi.wayne.edu/pdf/assessing_mental_health_concerns_in_adults_with_id.pdf
This resource provides an overview of the various measures used to assess mental health concerns in adults with an ID.

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

www.rcpsych.ac.uk/usefulresources/publications/books/rop/1606242094.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

www.med.monash.edu.au/oppm/research/davpsych/dbc.html
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.

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

www.dmld.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.

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

www.rcpsych.ac.uk/publications/collapersreports/op/op48.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.
Key Components of Accessible Mental Health Services

Multidisciplinary Approach and Interagency Collaboration

“Understanding challenging behaviour requires the formation of a collaborative partnership between mental health professionals and others involved with the person. This collaboration will underpin further intervention and support.”

– Child Psychiatrist, with a special interest in ID and autism

Specific Interagency Collaboration for Challenging Behaviour

There are multiple factors which contribute to challenging behaviour in people with an ID. These can include unmet environmental needs, communication needs, and mental and physical disorders. Research indicates that people with an ID are more vulnerable to stress and make less use of effective coping strategies, which may also contribute to the development of challenging behaviour. Contributing factors may interact,

For this reason, it is essential that mental health and disability service providers collaborate in the comprehensive assessment of challenging behaviour and in its subsequent management. Mental health service providers will be involved in identifying behaviour arising in whole or in part from mental disorders, and in considering the possible contribution of physical health conditions. Collaboratively, mental health providers will work together with other services such as disability, to implement a comprehensive approach to the management of challenging behaviour.

Interagency collaboration and a multidisciplinary approach will ensure services are coordinated and clients are provided with person-centred care.
Public Mental Health Services

- long-term accommodation models for people with an ID and mental disorders, including those with challenging behaviours; and
- assertive outreach and inpatient assessment and treatment models for people with an ID and mental disorders, including those with challenging behaviours.

Private Mental Health Services

- reviewing psychotropic medication use, especially in complex situations, including:
  - the presence of complex medical comorbidities;
  - situations of diagnostic uncertainty;
  - the emergence of unexpected or severe side-effects, or a new medical disorder during the course of treatment; and
  - when medications, including pro re nata (PRN) are given primarily as a treatment for challenging behaviour.

Specialised ID Health Services

- Developing skills 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;
For All Mental Health Service Providers

- Responsibilities include:
  - Recognising people with an ID, including those with challenging behaviour, as core business
  - Provision of accessible mental health services to a person with an ID and their carer/s
  - Providing information for consumers and their families using easy-to-understand language or using augmentative and alternative communication where appropriate
  - Working in a collaborative and coordinated manner with other supports
  - Supporting return and maintenance of optimal functioning
  - Ensuring linkage to the client’s primary health care practitioner to facilitate continuity of care
  - Fostering the development of skills in ID mental health
For Disability Services

- Responsibilities include:
  - Recognition that many people with ID and challenging behaviour will require specific mental health supports
  - Determining and documenting local and regional pathways to accessible mental health services (GPs, specialists, ID health and mental health experts)
  - Working in a collaborative and coordinated manner with mental health and behaviour supports
  - Considering joint capacity building with mental health services especially in challenging behaviour
  - Fostering the development of skills in ID the intersection between mental health and challenging behaviour
What Could Local Capacity Building Look Like?

- Community hub model for the conduct of joint multidisciplinary clinics, with focus on both mental health and behaviour
- Joint disability/mental health working groups
- Service pathway and referral maps
- Collation of local resources and specialists
- Network of skilled care providers: general practitioners, psychologists, psychiatrists, physicians, allied health practitioners
- Hospitalisation protocols for people with multiple or complex disabilities
- Development of specific expertise and capacity within large NGOs
- Preventative mental healthcare in a community setting
Summary

- Policy and service models give mixed messages about where challenging behaviour and its intersection with mental health fits
- Data supports this area as shared space
- The mental health workforce should have skills in assessing and managing challenging behaviour and its intersection with mental ill-health
- Service models should accommodate capacity for mental health services to assist in the assessment and management of challenging behaviour
- Some developments and resources available to assist this process
3DN February 2014
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