The Guide

Accessible Mental
Health Services
for People with an
Intellectual Disability

A Guide for Providers

The Guide is available for download at 3dn.unsw.edu.au/the-guide or via the Department of Health, Mental Health Publications page.

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Cover artwork

Rachelle Rodriguez, Coloured person, 2012, Studio ARTISTS

Daniel Kim, Poppy, 2012, Studio ARTISTS

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Artwork

Artworks featured throughout The Guide have been produced by artists in the studios of Miroma and the Studio ARTISTS collective.

Miroma supports clients with disabilities through a range of person-centred vocational programs including those in the creative arts and crafts. Miroma is a division of Inala that provides community participation programs and lifestyle supports for individuals with disabilities. For more information visit: www.inala.org.au

The Studio ARTISTS collective caters to adults with disabilities who have a vocational interest in the arts. These individuals have developed skills and emerged as artists through their involvement in a broader Studio ARTES program. For more information visit: www.studioartists.com.au

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The Vision

Accessible mental health services for people with an intellectual disability.

Executive Summary

People with an intellectual disability experience mental ill health at a rate which far exceeds that of the general population. The vulnerability to mental disorder is complex, and arises from an interplay between the intellectual disability and other medical, social and psychological factors.

Despite the over-representation of mental disorders in people with an intellectual disability, access to mental health care falls far short of what is required to meet the needs of this population. Many people encounter significant barriers which prevent timely access to appropriately skilled mental health supports and services. Mental health professionals and services are often challenged by the complex needs of people with an intellectual disability.

People with an intellectual disability, family and carers and professionals from mental health, disability and other services, agree that substantial improvement in access to mental health supports and services is required. The Guide has been developed as a practical framework for the development of accessible mental health services. It provides assistance to professionals and to services to improve access to high quality mental health care for people with an intellectual disability.

The Guide takes an approach which is underpinned by a human rights framework. This framework stipulates the rights of people with disabilities to accessible health supports and services, including those needed as a result of the disability. All mental health professionals and service providers are encouraged to embrace this responsibility to strive to ensure equal access, and to deliver the highest attainable standard of mental health care to people with an intellectual disability.

People with an intellectual disability and mental disorders often have complex needs, which require a coordinated approach across multiple service sectors including mental health, health and disability. The Guide highlights practical steps which can be taken to enhance communication, and cross-sector collaboration. This includes a strong emphasis on inclusive and person-centred approaches, involvement of family and carers, and the development of service pathways with interagency cooperation.

The Guide has been developed collaboratively by representatives from mental health, health, disability, consumer advocacy and other relevant agencies. The process reflects the collaboration that is required to ensure that people with an intellectual disability have access to high quality mental health services in a uniform manner across Australia.

Nationally, there is much to be done at a policy, resource and provider level before mental health services are fully accessible for people with an intellectual disability. However, change begins with the individual mental health professional and the local service. The Guide encourages incremental steps commencing with reasonable adjustments to practice and services, the development of expertise and capacity, and adopting a culture of accessibility. Such steps can have a major impact on the mental health and well-being of people with an intellectual disability.

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 Intelligent Quotient (IQ) score of approximately 70 or below. Current diagnostic criteria emphasise measurement of adaptive functioning rather than reliance on IQ scores alone[1]. 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.

Artwork by Margaret Barton, 2013, Miroma

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[2, 3].

Despite this, many people with an ID experience major barriers when trying to access mental health services[4]. The development of accessible mental health services for people with an ID in Australia lags behind internationally accepted practice[5]. 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 free or affordable mental health care.

PURPOSE
OF THIS GUIDE

This Guide offers a framework for mental health professionals to improve the accessibility and quality of mental health care for people with an ID.
It outlines:

- the nature of ID and its co-occurrence with mental disorders;

- how mental disorders may present in people with an ID;

- the principles which underpin the provision of mental health care to people with an ID;

- a series of tools for inclusive practice, including examples of best practice;

- a range of reasonable adjustments for mental health services to support the diverse needs of people with an ID; and

- the implications for each major component of the mental health system.

HOW THIS GUIDE
WAS DEVELOPED

The development of this Guide was led by the Chair of Intellectual Disability and Mental Health from the Department of Developmental Disability Neuropsychiatry (3DN), School of Psychiatry, University of New South Wales.

A Core Reference Group (CRG) was convened by invitation to national experts in ID mental health. The CRG included clinical professionals, policy makers, community support staff and health service managers (see p. 43 for CRG members). The CRG participated in a series of online and teleconference consultations to inform the content of the Guide and provide feedback on each phase of its development. Concurrently, a search was conducted to identify ID and mental health literature including existing national and international policies and service frameworks. Together, the CRG consultations and literature search informed the development of the core domains and content of the Guide.

Drafts of the Guide were reviewed at the National Roundtable on the Mental Health of People with Intellectual Disability in May 2013, and subsequently by the CRG, Roundtable participants and the Australian Government Department of Health.

Funding for the development of the Guide was obtained by the UNSW Chair of Intellectual Disability and Mental Health following a submission to the Australian Government Department of Health. The NSW Council for Intellectual Disability and the Australian Association of Developmental Disability Medicine were partners in the submission to the Department of Health.

HEALTH CARE SETTINGS TO WHICH THIS GUIDE APPLIES

This Guide provides recommendations for the mental health care of people with an ID who use health care services in Australia, including:

- general practices;

- community mental health services (including child and adolescent, youth, adult and older persons);

- office-based mental health and health practices, including private practices;

- inpatient and outpatient mental health facilities;

- forensic mental health services;

- other services such as those within Aboriginal and Torres Strait Islander and transcultural mental health services;

- mental health services within drug and alcohol services;

- specialised intellectual disability mental health services; and

- other relevant allied health and mental health services.

This Guide offers a framework for mental health professionals to improve the accessibility and quality of mental health care for people with an ID.

HOW TO USE THIS GUIDE

The Guide addresses a broad range of mental health professionals to improve access to mental health services for people with an ID. It is a 'quick reference' document which enables professionals and services to make reasonable adjustments and take practical steps to improve accessibility.

The Guide serves to facilitate improved access to mental health services for people with an ID.

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The Guide is organised in a tiered manner. The Introduction and Background sections present an overview of the mental health needs, and highlight the barriers to accessing appropriate mental health services for people with an ID. Guiding principles are presented to underpin practice.

Key components are identified which establish the significant elements of service delivery for this population.

Implications are detailed for all professionals, and for various mental health service providers. To assist in implementation, these are divided into implications for individuals, and for organisations. Key roles and responsibilities are outlined, followed by further recommendations to assist the development of more comprehensive services.

The Guide contains specific implications relating to broad service categories including: primary health care, public mental health, private mental health and specialised intellectual disability mental health.

Tools for Inclusive Practice are also included in the Guide to assist professionals by highlighting the availability of a broad range of resources which enhance practice.

If viewed electronically, a series of hyperlinks are embedded throughout the Guide to provide quick access to relevant sections and resources. These resources are also provided within the Appendices.

Other professionals and service settings are integral to the broad support system for the mental health and wellbeing of people with an ID. These include disability, education, general health and other human service organisations. The Guide encourages agencies to operate in an integrated and cohesive manner to provide optimal person-centred care.

The Guide also acknowledges the importance of families and carers in supporting mental health and well-being in people with an ID. Specific resources for consumers, families and carers are provided in the Tools and Resources for Consumers, Family and Carers and the Advocacy Services and Guardianship sections.

The Guide encourages agencies to operate in an integrated and cohesive manner to provide optimal person-centred 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[2, 3, 6]. This predisposition to mental ill-health is apparent across the lifespan, including in children, young people and adults[6-8]. At any one time, an estimated 20-40% of people with an ID will be experiencing a mental disorder of some kind[2, 3, 6, 9]. 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[3, 9, 10]. In addition, higher rates of dementia are apparent in older persons with an ID compared to the general population[11].

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,[12] as can developmental brain abnormalities and pharmacological treatments and their side effects[13]. 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[11, 14, 15].

The presence of an ID usually affects a person's coping skills and autonomy, creating greater susceptibility to stress, and thereby increasing psychological vulnerability[16]. 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[17-19]. Furthermore, people with an ID experience higher rates of physical and sexual abuse [20] which can further magnify their vulnerability to mental ill-health.

Artwork by Heather McCarthy, 2013, Miroma

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 mainly present as problematic behaviours[21, 22]. 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[23, 24]. 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

BARRIERS TO ACCESS

Available data suggests that access to mental health treatment is poor and problematic for people with an ID with illnesses often being misdiagnosed, unrecognised, and poorly managed[25]. International studies suggest a low rate of accessing mental health care for people with an ID[26-29]. A long-term Australian study found that fewer than 10% of young people with an ID and clinically significant psychopathology accessed appropriate treatment over a 14-year period[6]. By contrast, in Australia, about 35% of individuals with a mental disorder in the general population receive specific mental health intervention in a single year[30]. The low rates of accessing mental health care suggest under-treatment and potential for mental health problems to become chronic[21, 29].

"It took many years to get the help 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

There are a number of potential barriers to accessing mental health treatment and supports for people with an ID. These include:

- factors related to the person's ID which complicate assessment[21, 31];

- lack of awareness of symptoms both by the person or their family and carer(s)[32];

- stigma and exclusion from services[32]; and

- limited practical support to access services.[28]

Some barriers relate to service factors, such as inadequate training and awareness in mental health professionals[32, 34], diagnostic overshadowing, lack of ID specific mental health services[35, 36] or a lack of coordination between agencies. Systemic barriers include poverty[18], limited education[32, 37], lack of inclusive service models and policy[5], and the lack of data to evaluate service access.

Artwork by Rochelle Rodriguez, Coloured People, 2013, Studio ARTISTS

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-focused, and evidence-based services[38]. These should be built around both community-based and specialist social support, and integrated with mental health, general health and disability services[31, 39]. 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)[40] (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[40].

Mental health consumers with reduced capacity, including those with an ID, should be supported to understand and exercise their rights[38].

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[41]. 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 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 supports[41, 42].

> *"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

the supports offered to each individual promote independence to the fullest extent possible.

Mental health services should also support decision-making for people with an ID, assisting the person in understanding, considering and communicating their choices. These principles must be reflected in the various approaches to the capacity and consent process (see *Decision-Making and Mental Health Care* section p. 16).

RECOVERY-ORIENTED PRACTICE

'From the perspective of the individual with mental illness, recovery means gaining and retaining hope, understanding of ones abilities and disabilities, engagement in an active life, personal autonomy, social identity, meaning and purpose in life, and a positive sense of self.'
– The National Standards for Mental Health Services[43] (2010, p. 42)

Recovery-oriented mental health practice strives to support individuals to build on their strengths so that they can take as much responsibility for their lives as possible at any given time. The individual is viewed as an expert in their own life and lived experience, while the mental health worker can share expertise in treatment options[44].

For people with an ID, recovery-oriented practice relates specifically to mental health rather than support for their ID per se. As with the general population, recovery-oriented mental health practice moves the focus away from simply ameliorating mental disorders towards

more holistic care. It recognises that recovery outcomes are specific to the person with an ID at any age, and encompass social inclusion and quality of life[43]. The emphasis is on providing long term supports that promote ongoing well-being. Adopting a recovery-oriented approach for people with an ID may require additional effort and resources because of the complexity of supports needed.

Within the mental health context this begins with a thorough and appropriate mental health assessment. It requires a subsequent collaborative partnership approach between health and disability professionals and services. This partnership approach should also include collaboration with the person with an ID and their carer(s) and families. This will ensure that mental health services can support individuals with an ID and their family and carers in a way that is consistent with their particular values and goals.

EVIDENCE-BASED

Decisions made by mental health professionals should be informed by the best available evidence. Providing evidence-based interventions can assist in achieving the best possible mental health outcomes[43].

This means that professionals should continually seek to enhance their knowledge of new and existing interventions. Sources of evidence can include clinical research in the areas of assessment and management of mental disorders in people with an ID. If there is no specific information available, best practice can include interpreting results of studies in the general population, and applying them where appropriate.

Mental health professionals can also significantly contribute to the evidence-base by sharing innovative and new interventions they undertake within their networks.

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 cancelling 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.

> *"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

Effective Communication

People with an ID and health professionals have identified poor communication as a barrier to accessing health care[45]. 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.

It is imperative that mental health professionals identify the most appropriate means of communicating with the individual with an ID and adapt their approach accordingly. Where the professional is unfamiliar with the person, they should ask the person (or those accompanying them) how they prefer to communicate, and if there is any particular method or communication aid that should be used. For example, a person with an ID may use specific augmentative and alternative communication strategies such as gestures, signing (for example from the Key Word Sign vocabulary), or aided communication through the use of specific devices or an interpreter.

A family member or carer may also be able to assist in the communication process, or may perform as an interpreter.

A reflective approach to communication is preferable, in which the professional makes use of feedback to monitor and adapt the way they are communicating. Adjustments may be required in many aspects of communication, including speed, complexity of language and concepts, non-verbal cues, use of gestures and supportive body language. It is important to clarify whether the person with an ID has understood what has been said.

Furthermore, as awareness of mental health and medical issues is variable, clarification should be sought regarding the accompanying person's understanding. Further information regarding communication with people with an ID is contained in Appendix 9 - *Other Resources*, p. 62.

It is important to clarify whether the person with and ID has understood what has been said.

> *"Respectful interactions are not only mutually rewarding but also assist the process of recovery."*
>
> – Mental health professional, ID mental health service

Decision-Making and Mental Health Care

Inclusive practice will engage the person with an ID in decisions regarding their mental health care to the greatest extent possible.

With the exception of emergency treatment, a person with an ID cannot be treated without consent. Mental health professionals must be able to evaluate the person with an ID's capacity to consent to treatment, and must engage the person, along with their delegated decision-maker where appropriate, to the fullest extent possible. Capacity is situation and decision-specific. A person may be able to consent to simple but not complex treatments, and may be more able to consent in a calm, unhurried situation.

It should be recognised that consent is often an emerging process (rather than a single event at a given point in time), as the person gains experience with the assessment and treatment process. With this in mind, it is important for mental health professionals to regularly revisit consent throughout their involvement with the person, and to allow for changes in the person's capacity and in their views in relation to the treatment as treatment progresses.

Parents or legal guardians of children with an ID are legally responsible for decisions about the mental health care of those children. Many adults with an ID have capacity to make informed decisions about mental health treatments, but may require additional time, explanation and support to do so.

When an adult with an ID is unable to make decisions about treatments on their own behalf, a 'person responsible' under the relevant guardianship legislation or a legally appointed guardian may act as the substitute decision-maker. In some situations, treatment for a mental disorder may be administered under a specific Mental Health Act. A list of specific guardianship and administrative bodies for each State is provided in *Advocacy Services and Guardianship* in Appendix 4, p. 52. (See also CIDs Fact Sheet on Consent to Medical Treatment).

Working with Family and Carers

> **'The mental health service recognises, respects, values and supports the importance of carers to the wellbeing, treatment, and recovery of people with a mental illness.'**
> – The National Standards for Mental Health Services[43] (2010, Standard 7, p.16)

Carers, including family members and support workers, are central in providing support to people with an ID including those with mental illness. Mental health professionals should engage family and carer(s) as collaborative partners in the assessment and management of the mental health of a person with an ID to the appropriate extent, taking into account the preference of the person with an ID, their level of ID and the severity of their mental illness. The person with an ID may have a preference to attend the consultation on their own, and such requests should be respected where possible.

Family members and support workers provide important information relevant to the assessment and diagnosis of mental disorders in people with an ID which can assist the clinician to determine the treatment response. Mental health professionals should recognise that family members and support workers vary greatly in their experience and skills in ID mental health. This should be taken into account in the interpretation of information provided. Tools and resources for consumers, family and carers can be found in Appendix 3, p. 50.
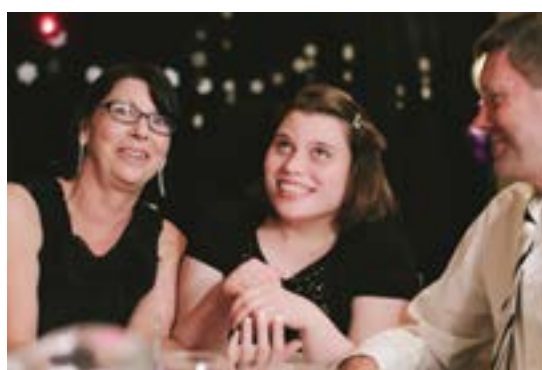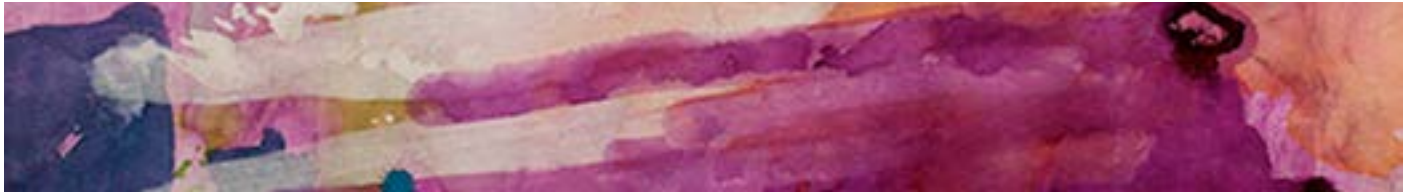
"George is 9 years old and has a moderate intellectual disability and other general health problems. Recent family changes worsened his mood and behaviour. His mother had increasing difficulty managing his needs. George and his mother were referred to a service which offered joint GP-psychiatrist assessments. The assessment addressed George's medical issues and identified explanations for the change in his mood and behaviour. Furthermore, his mother's unaddressed mental health needs were also identified and addressed, resulting in significant improvement in the way in which she was able to manage and care for her son."

– Psychiatrist, ID mental health specialist

ACCESS TO MENTAL HEALTH SERVICES

People with an ID have a right to timely access to mental health services at any stage of life, including proactive primary health care and health promotion strategies. Having an ID should not be a reason for exclusion from mainstream mental health services.

Adjusting mental health services to meet the needs of people with an ID will not only enable services to meet their needs as part of prescribed rights and responsibilities under the United Nations CRPD, but is likely to improve the quality of services[38, 40].

People with an ID should:

- have their initial mental health care needs met by mainstream mental health services, including those in primary care, and private and public mental health services;

- follow typical pathways through mental health services, which should be clearly identifiable to the person with an ID, their family and support workers;

- receive coordination of mental health, health and disability supports during their period of mental health care through collaborative partnership between various service providers. This may include practitioners and professionals in primary care, private mental health services, disability services, public mental health services, non-government organisations and support services for particular groups such as Aboriginal and Torres Strait Islander and multicultural support services; and

- be directly assessed in a thorough manner by the treating clinician, so that the impact of symptoms on the person's behaviour and function is adequately documented.

# ACCESS TO SPECIALISED INTELLECTUAL DISABILITY MENTAL HEALTH SERVICES

Access to specialised ID mental health services is currently very limited and varies greatly across Australia. Where they do exist, specialised services form a valuable component of a comprehensive mental health service for people with an ID. Specialised ID mental health services may:

- provide advice and a referral pathway for mainstream health and mental health services;

- offer case review and second opinions in situations of increased complexity;

- provide longer or secondary consultations for more comprehensive assessment, observation and care;

- provide advice in developing strategies for service enhancement, including educational programs, development of service models and interagency collaborative initiatives;

- provide time-limited treatment and management until adequate mainstream services are available; and

- improve accessibility to services through the utilisation of e-medicine, such as Telemedicine, particularly in rural and remote areas.

"The breakthrough came when my daughter who has complex health problems, was admitted for an assessment by a specialist in disability and mental health. Her medication was sorted out and she has benefited from consistent specialised psychiatric care since then."

– Barbara, parent and carer
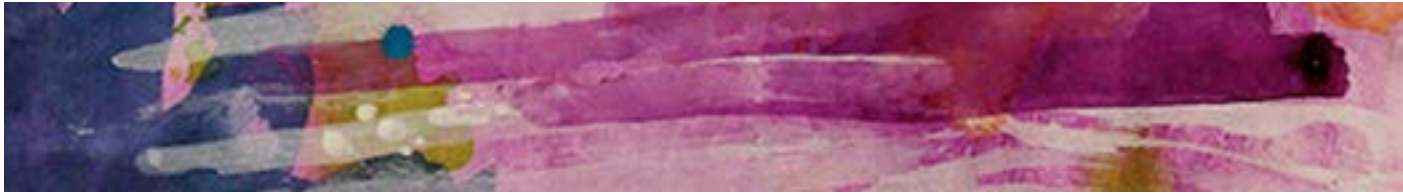
IDENTIFICATION OF CARE PATHWAYS

Mental health care providers can improve access for people with an ID by:

- identifying a clear clinical pathway through their service which is available to people with an ID, including those with complex needs;

- providing accessible information to people with an ID and their family and carer(s) regarding mental health services;

- designating ID mental health clinical care coordinators within public mental health services to coordinate access, triage and referral to appropriate components of health and disability services;

- developing specific ID mental health teams within public mental health services with capacity to assess and manage mental health crises, assess priority referrals from disability services, provide consultation to inpatient units and provide consultation to community mental health services;

- developing systems for coordinated transition of people with an ID between mental health service providers at various transition points e.g. child – youth, youth – adult, adult – older person; and

- ensuring appropriate transfer and handover of health and care information with other individuals and services involved in the care pathway of the person with an ID.

TRAINING AND EDUCATION FOR PROFESSIONALS

Australian research suggests that mental health professionals lack confidence in ID mental health[25, 46, 47], and this is likely to be true of other clinician groups as well. Training and education is one mechanism for improving the capacity of mental health care providers to meet the needs of people with an ID. Whilst specific training resources in this area require further development, a number of resources are currently available (see Appendix 7 – *Training and Education*, p. 57).

Training and education initiatives should be:

- broad-based and include mandated minimum content in undergraduate and postgraduate education in relevant disciplines (medicine, nursing, psychology, allied health, specialist general practice and psychiatry training);

- interdisciplinary and culturally inclusive in nature to improve the ability of professional groups and service providers from different backgrounds to provide coordinated mental health care;

- available in a flexible format, for example online, to allow access when the mental health professional requires it;

- available in a tiered manner at fundamental, advanced and extension levels to address the needs of different mental health care providers:

  - accessible at a basic level to all primary care, non-specialist community care and non-mental health specialist care services;

  - accessible at basic and advanced levels to specialist community, emergency, outpatient and inpatient mental health care providers; and

  - accessible at extensive and specialised levels to ID-specific health and mental health care providers.

Mental health professionals lack confidence in ID mental health.

———

MULTIDISCIPLINARY APPROACH AND INTERAGENCY COLLABORATION

People with an ID may be consumers of a range of services in addition to mental health services, including general health, disability and education. Best practice means engaging in active collaboration between service providers from various sectors, and service providers within each sector. A multidisciplinary approach, where collective knowledge is shared, will minimise duplication of information.

In some areas, clinicians within mental health services work as part of a multidisciplinary team that includes psychiatrists, psychologists, nurses, occupational therapists and other staff, to provide comprehensive care[48]. Mental health initiatives such as *headspace* (see *Glossary*, p. 40), function as a one-stop-shop providing holistic and collaborative care.

For people with an ID, interagency collaboration and a multidisciplinary approach will ensure services are coordinated and clients are provided with person-centred care. This may entail:

- consent to share information about the person with an ID with other service providers; a process for sharing this information; and exchange of this information in a format understandable by each service provider;

- formal strategies to enhance cross-sector collaboration including coordinated case management (for an example see MoU and Guidelines between ADHC, Department of Human Services NSW and NSW Health in the Provision of Services to People with an Intellectual Disability and Mental Illness, NSW Health 2010[49]);

- considering families and carer(s) as partners and/or experts in the care of the person with an ID;

- cohesive and collaborative sharing of health information and health records (including electronic) with others involved in the care of the person to facilitate constructive coordination of care;

- mental health service providers enabling joint assessment of people with an ID with other relevant agencies such as disability services and education[47];

- developing capacity for urgent referrals to mental health services from disability services, and vice versa;

- capacity for co-management and coordination of mental health and disability services for people with an ID and mental disorder, including sharing resources, expertise and clinical services between disability and mental health sectors;

> *"Working collaboratively with other professionals and across service boundaries allows a comprehensive formulation. This is particularly helpful in complex cases where it can be hard to identify underlying mental health issues."*
>
> – Psychologist, disability service

- capacity for multidisciplinary review of complex cases which bring together representatives of different agencies (e.g. Multiple and Complex Needs Initiative - MACNI, see also Appendix 2 – *Examples of Models of Best Practice* p. 46);

- joint education and training initiatives that engage representatives from different components of the mental health service system (primary care, specialist, tertiary and cross disciplinary)[50]; and

- joint education and training initiatives that engage sectors relevant to the support of people with an ID (primarily those in disability, health, education and community services).

> *"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[51]. 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[16]. Contributing factors may interact,

making it complicated to clearly differentiate between them. Furthermore, it can be difficult to determine whether the behaviour is arising from an underlying mental disorder.

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.
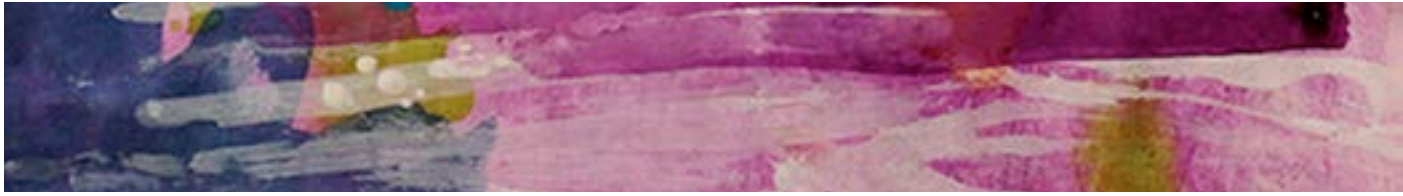
DATA COLLECTION AND EVALUATION

In other countries, data collection and interrogation has been pivotal to the improvement of access to ID mental health services. Currently there is no systematic collection and analysis of data which reflects mental health services and mental health outcomes for people with an ID nationally in Australia[52]. Data should be collected at a local level, documenting the capacity of health services in ID mental health, including the accessibility of services, development of clinical pathways, training and education of staff and availability of specialist ID mental health services.

It would also be beneficial to have a standardised national collection and interrogation of mental health service (MHS) data. This should incorporate Commonwealth Medicare Benefit Schedule data, Pharmaceutical Benefits Scheme data and State-based MHS data collections. This data could be used to determine service use and mental health outcomes for people with an ID nationally and subsequently linked to data collected under the National Disability Insurance Scheme.

INCLUSION IN POLICY DEVELOPMENT

Leading international examples (such as those from the United Kingdom[38, 53, 54]), demonstrate that proactive policy development is a key component in improving of health and mental health care for people with an ID. Policy development at all levels in mental health should routinely include the specific mental health needs of people with an ID and should:

- be informed by the *Guiding Principles* previously described (p.11);

- uphold the right to access to health care for people with disabilities;

- engage people with an ID where possible;

- aim to directly address the health and mental health inequalities experienced by people with an ID; and

- be coordinated, with a whole-of-government approach.

"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

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 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 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.

IMPLICATIONS FOR PRIMARY HEALTH CARE

Primary health care is usually the first point of contact with mental health services for people with an ID and the pathway to further treatment, if required. Primary health care providers include general practitioners and practice nurses, who provide the majority of front-line mental health services for people with an ID. The following recommendations may also be relevant to other services which also serve as an entry point to further mental health care including emergency departments and ambulance services.

In relation to people with an ID and co-occurring mental disorders, the key roles and responsibilities of Primary Health Care Services include:

For the Organisation

- Ensuring staff are mindful and adopt flexible approaches when communicating with clients with an ID.

- Ensuring that staff understand and implement accessible, person-centred mental health care, by adopting an inclusive approach.

- Ensuring staff are familiar with referral and access pathways for local or regional mental health, disability services and specialist ID mental health services.

- Providing ongoing training and professional development relevant to ID mental health.

For the Individual

- Prioritising early identification and management of physical and psychiatric comorbidities.

- Conducting annual health checks that include screening for mental health disorders.

- Referring as appropriate to mental health service providers. This should take place in most circumstances unless the person has an uncomplicated presentation.

- Utilising initiatives such as the Better Access to Psychiatrists, Psychologists and General Practitioners through the Medicare Benefits Schedule (Better Access) Initiative and Access to Allied Psychological Services (ATAPS) program.

- Obtaining information from various medical and non-medical sources to inform development of the care plan and establish a system for sharing this information with other services involved.

- Developing multidisciplinary care plans which adopt a bio-psycho-social model which engage the range of relevant ID supports.

- Providing regular reviews to monitor the impact of intervention on mental health, and to monitor its impact on physical health and medical comorbidities.

- Regularly screening for side-effects in those people with an ID who are prescribed psychotropic medication. Liaising with pharmacists to ensure safe and comprehensive delivery of medication is also recommended.

- Providing mental and physical health promotion strategies in accessible formats.

- Advocating for patients and ensuring the provision of the best possible supports.

"When both mental health and general health conditions are addressed, the engagement with the person increases and quality of life improves."

– Mental health professional, disability service

Further improvement of the mental health care of a person with an ID by a comprehensive Primary Health Care Service would involve:

For the Organisation

- Facilitating staff to provide longer consultations and home visits/outreach for people with an ID.

- Incorporating non-medical services as part of the care plan. For example, services focussed on activity and participation including sport, recreation, leisure and other social inclusion activities.

- Providing facilities and environments which are appropriate and comfortable for people with an ID, taking into account the need for varying levels of stimulation.

- Developing partnerships with local or regional specialised ID health and mental health services.

- Promoting networking and training opportunities in ID mental health such as those available through the Mental Health Professionals Network Ltd, the Royal Australian College of General Practitioners and the General Practice Mental Health Standards Collaboration.

- Fostering staff development of skills in ID mental health through the provision of education and access to training resources.
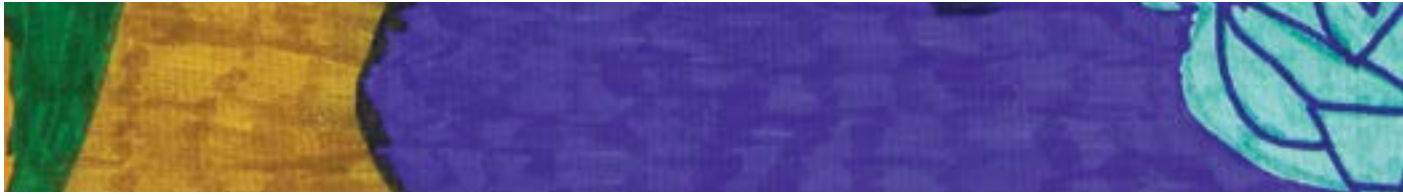
For the Individual

- Booking longer consultations, in recognition of the complexity of this group and the need to work with family, carers and disability specific supports.

- Facilitating and encouraging routine return visits to address usual care and normalise the primary care experience.

- Ensuring awareness of the Chronic Disease Management Medicare items on the Medicare Benefit Schedule (MBS) and how they can be applied to people with an ID and a mental health disorder.

- Utilising Medicare Locals to access tailored community health services and available resources including mental health support.

- Where the provider of the service is not the usual health care practitioner, ensuring linkage back to the client's regular primary health care practitioner (most commonly a general practitioner) to ensure continuity of care.

- Including ID mental health in the staff member's continuing professional development program, with a focus on:

  - developing a more detailed understanding of the presentation, assessment and management of mental disorders;

  - developing an understanding of the association between mental and physical ill health on behaviour in people with an ID;

  - familiarisation with resources which support clinical practice including developing knowledge of clinical assessment tools and management guidelines for use in primary care.

- Being aware of the obligations of local mental health services toward people with an ID, and knowledge of referral procedures.

IMPLICATIONS FOR PUBLIC MENTAL HEALTH SERVICES

Public mental health services include individuals from a range of disciplines and with a range of professional expertise. These are represented in diverse service components including crisis care, acute and non-acute inpatient mental health facilities, outpatient and community based mental health services and in specialty groups by location (such as consultation liaison services) or by age (child and adolescent, youth, adult, older persons). Professionals from these groups provide mental health assessment, care and management of varying intensity and duration.

In relation to people with an ID and co-occurring mental disorders, the key roles and responsibilities of Public Mental Health Services include:

For the Organisation

- Recognising and promoting 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 mainstream mental health services.

- Developing partnerships with local or regional disability services.

- Understanding the processes for referring to disability and related services, and developing networks and partnerships with local services.

- Developing staff resources outlining the availability of, and access to, local or regional specialised ID health and mental health services.

- Identifying care pathways through typical service components, including:

  - Crisis or emergency mental health care for all age-groups;

  - Child and adolescent and youth mental health services;

  - Forensic mental health services;

  - Older persons mental health services;

  - Community and outpatient care;

  - Acute and non-acute inpatient care settings;

  - Psychiatric rehabilitation services;

  - for age-related transitions, including those from related disciplines such as developmental paediatrics; and

  - for mental health care during a non-psychiatric episode of care.

- Developing accessible information (e.g. Easy English, Plain English or modified materials) where appropriate for consumers and their families.

- Developing formal protocols to enable staff to recognise people with an ID and understand their needs on admission, perform assessment of risk, and actively plan discharge.

For the Individual

- Competently conducting a comprehensive mental health assessment.

- Developing capacity for comprehensive management plan which engages key supports (e.g. workplaces, schools and educational institutions).

- Conducting and participating in regular case reviews to coordinate the mental health intervention.

- Regularly reviewing psychotropic medications and monitoring any potential side-effects.

- Being aware of identified care pathways through typical service components.

- Being familiar with referral and access pathways for local or regional disability services.

- Developing partnerships with local or regional disability services.

- Being aware of the availability of, and access to, local or regional specialised ID health and mental health services.

- When appropriate, referral for a second opinion or to a specialist ID mental health service if available. This will usually be necessary for situations of high complexity or where treatment response is lacking.

"A young man with a moderate intellectual disability and possible schizophrenia was referred to the service. Following cyclic periods of being settled and episodes of verbal and physical aggression, a comprehensive assessment identified probable bipolar disorder with autistic spectrum disorder. After appropriate treatment and reassessment of medication, there was dramatic improvement, including reduction of Crisis Team contact and inpatient stays."

– Psychologist, ID mental health service

Further improvement of the mental health care of a person with an ID by a comprehensive Public Mental Health Service would involve:

For the Organisation

- Fostering staff development of skills in ID mental health through the provision of education and access to training resources.

- Engaging with the academic sector to facilitate links to highly specialised expertise, research and training opportunities.

- Developing joint initiatives between local disability and mental health services including:

- the capacity for the conduct of joint assessments of people with an ID and possible mental health disorder;

- the capacity for priority referral of urgent cases from disability or health sector to one another;

- establishing regular meetings between designated mental health and disability staff to discuss specific cases;

- conducting joint training and education initiatives;

- the establishment of pathways for case escalation;

- establishing agreements between organisations for consistent coordination between services, such as a Memorandum of Understanding (MoU);

- 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.

- Identifying existing public mental health sector staff with expertise in ID mental health who can act as 'ID mental health champions' in each local area.

For the Individual

- 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;

  - high level expertise in the management of mental disorders in people with an ID, including an awareness of the role and application of non-pharmacological treatments;

  - an in-depth knowledge of functional assessment and applied behaviour analysis; and

  - understanding the application of diagnostic and classification systems for mental disorders in people with an ID.

- Contributing to capacity building including to the training of health professionals in ID mental health.

IMPLICATIONS FOR
PRIVATE MENTAL HEALTH SERVICES

The private mental health sector provides an essential service to people with ID. Private practitioners often provide an enduring role in the mental health support of a person with an ID.

In relation to people with an ID and co-occurring mental disorders, the key roles and responsibilities of Private Mental Health Services include:

For the Organisation

- Ensuring that employees understand and implement the provision of accessible, person-centred mental health care.

- Establishing collaborative links with public and private mental health services, and disability sector services.

- Promoting staff familiarity with referral and access pathways for local or regional disability services.

- Ensuring staff are mindful and adopt flexible approaches when communicating with clients with an ID.

For the Individual

- Competently conducting a mental health assessment.

- Having the capacity to develop a comprehensive management plan which engages key supports for the person with an ID.

- Conducting regular reviews to implement the mental health intervention.

- Regularly reviewing side-effects of psychotropic medications.

- Being familiar with referral and access pathways for local or regional disability services.

- When appropriate, referring for a second opinion within or outside the private sector, or to a specialist ID mental health service if available. This will usually be necessary for situations of high complexity or where treatment response is lacking.

- Raising awareness that persons with an ID have the right to treatment in private health settings, wherever that may be.

Further improvement of the mental health care of a person with an ID by a comprehensive Private Mental Health Service would involve:

For the Organisation

- Providing facilities and environments which are comfortable and welcoming of people with an ID.

- Fostering staff development of skills in ID mental health through the provision of education and access to training resources.

For the Individual

- Providing home visits where necessary to people with an ID.

- 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;

  - high level expertise in the management of mental disorders in people with an ID, including an awareness of the role and application of non-pharmacological treatments;

  - developing an in-depth knowledge of functional assessment and applied behaviour analysis; and

  - detailed understanding of the application of diagnostic and classifications systems for mental disorders in people with an ID.

# IMPLICATIONS FOR SPECIALISED INTELLECTUAL DISABILITY MENTAL HEALTH SERVICES

While the availability of specialised ID mental health services varies greatly, they play a valuable role in certain settings. These settings may include:

- **within specialised ID health or disability services;**
- **as outreach services to schools, disability services or forensic settings;**
- **as tertiary services within mainstream public or private mental health services; and**
- **as part of an academic or university clinical service.**

Specialised ID mental health services work primarily to support other providers of mental health care by providing highly specialised assessment and management advice, facilitating training and development of the mental health workforce capacity, and contributing to policy, service development and research. It is therefore important that specialised services are available and are easily accessible.

"One of our worst times was when my daughter was admitted to hospital with prolonged delirium. We explained that she was usually a bright, sociable young woman with lots of friends and an excellent quality of life. The medical team disbelieved us and assumed she was always like she was on admission. We were told to put her in a nursing home. After discharge from hospital we accessed a specialist, and further treatment led to a complete recovery for our much loved family member."

– Michele, carer and parent
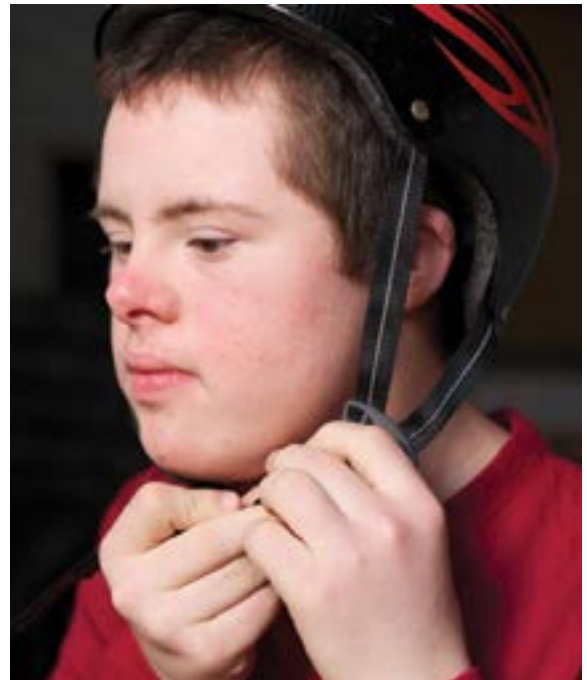
In relation to people with an ID and co-occurring mental disorders, the key roles and responsibilities of Specialised ID Mental Health Services include:

For the Organisation

- Developing a framework for collaboration and capacity including, but not limited to:

  - formalising of interagency referral paths;

  - developing interagency education and training; and

  - training of health professionals in ID mental health.

- Developing professional networks with local, regional, State/Territory specialist ID health and mental health clinicians and services.

- Being familiar with referral and access pathways for local, regional and highly specialised disability services.

- Developing formal protocols to recognise the presence of an ID when a person is admitted to a mental health service, to support their needs and address appropriate discharge planning considerations.

For the Individual

- Having detailed knowledge and application of person-centred approaches in clinical practice.

- Incorporating prevention and early intervention strategies in clinical practice.

- Performing a comprehensive mental health assessment.

- Developing and communicating a detailed formulation and management plan.

- Providing support to frontline public and private mental health service providers by:

  - providing diagnostic second opinions for frontline mental health professionals;

  - reviewing proposed management plans;

  - 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.

- Being aware, and fostering the activity of professional networks with local, regional, State/Territory specialist ID health and mental health clinicians and services.

- Being familiar with referral and access pathways for local, regional and highly specialised disability services.
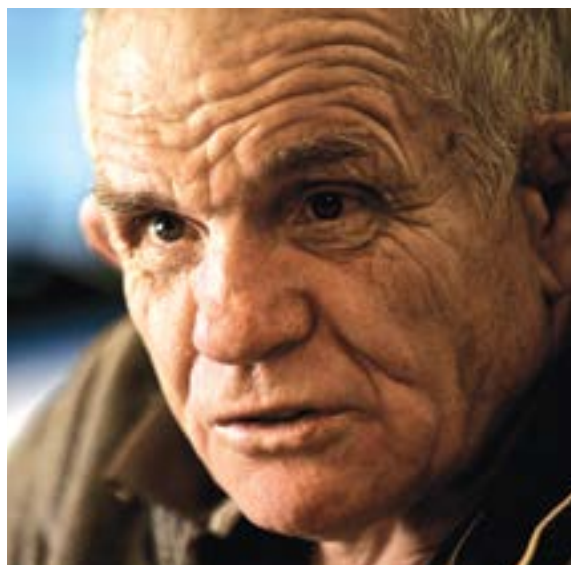
Further improvement of the mental health care of a person with an ID, a comprehensive Specialised ID Mental Health Service would involve:

For the Organisation

- Fostering the development of leadership capacity and peer support networks related to ID mental health services.

- Establishing formal links with academic ID health and mental health networks.

- Hosting ID mental health research projects which inform clinical practice.

- Leading the development of links between mental health and new initiatives in the health and the disability sector, including newly funded

initiatives such as the National Disability Insurance Scheme.

- Leading the development and implementation of data collection and evaluation systems specific to ID and ID mental health.

- Facilitating access to specialist inpatient beds to allow for diagnostic clarification and treatment trials of complex cases.

- Supporting systemic advocacy to improve access to, and the quality of, mental health support for people with an ID.

For the Individual

- Developing skills in ID mental health to an expert level, including:

  - an expert knowledge of the interactions between health and mental health conditions and challenging behaviour;

  - expert skills in the management of mental disorders in people with an ID, including the capacity to advise on the application of non-pharmacological treatments;

  - detailed knowledge of functional assessment and the practical applications of applied behaviour analysis; and

  - sophisticated understanding of the application, and limitations of diagnostic classifications systems for mental disorders in people with an ID.

- Being available to participate in complex interagency case reviews.

- Developing a comprehensive referral network with relevant medical, allied health and disability professionals.

- Engaging and leading peer support networks related to ID mental health services.

- Participating in expert consultation, service and policy development initiatives.

- Undertaking research which informs clinical practice.

- Providing clinical opinions in specific subpopulations including, people with an ID at risk of offending, those with age-related mental disorders, people with multiple and complex disabilities which are comorbid with mental disorders (e.g. combination of severe physical disability and ID).

- Advocating for improved access to, and quality of, mental health support for people with an ID.

Glossary

Access

The ability of consumers or potential consumers to obtain required or available services when needed within an appropriate time-frame.

Access to Allied Psychological Services

www.health.gov.au/internet/main/ publishing.nsf/Content/mental-boimhc-ataps

The Access to Allied Psychological Services (ATAPS) program allows general practitioners to refer patients who have been diagnosed as having a mental disorder of mild to moderate severity to a mental health professional to provide short term focussed psychological strategies and services. ATAPS is provided through Medicare Locals throughout Australia and complements the Better Access initiative (see below).

Adaptive functioning

A term to describe how well an individual copes with tasks across a range of domains required for everyday living, such as communication, self-care, practical skills and interpersonal skills.

Advocacy

Representing the interests and concerns of consumers, family and carers and providing support to enable them to represent themselves.

Better Access to Psychiatrists, Psychologists and General Practitioners through the Medicare Benefits Schedule (Better Access) Initiative

www.health.gov.au/mentalhealth-betteraccess

The national Better Access initiative seeks to improve treatment and management of mental illness by increasing community access to mental health professionals and team-based mental health care. General practitioners are encouraged to work more closely and collaboratively with psychiatrists, clinical psychologists, registered psychologists and appropriately trained social workers and occupational therapists.

Challenging behaviour

A term (not a diagnosis) to describe severe problem behaviours. Challenging behaviours have been defined as 'behaviours of such intensity, frequency or duration that the physical safety of the person or others is placed in serious jeopardy or behaviour which is likely to seriously limit or delay access to and use of ordinary community facilities'[55]. Challenging behaviour may be contributed to by a number of factors including: autistic spectrum disorder, psychiatric illness, personality disorder, environmental stressors, physical illness and behavioural phenotypes. Some common examples of challenging behaviour include aggressive outbursts, self-injury and socially inappropriate behaviour[56].

Complex needs

The term used to describe a range of multiple and additional needs that people with an ID may have. This can include people with severe ID and other developmental or physical disabilities, those that demonstrate challenging behaviours, and those that experience mental disorders.

Consumer

A person who uses or has used a mental health service.

Developmental disability

Disabilities that relate to 'differences in neurologically based functions that have their onset before birth or during childhood, and are associated with significant long-term difficulties' (*Therapeutic Guidelines Limited*, 2012, p.1)[57]. All intellectual disabilities are developmental disabilities, but not all developmental disabilities are associated with an ID. For example cerebral palsy is a developmental disability which may or may not be associated with ID.

Diagnostic overshadowing

The term 'diagnostic overshadowing' refers to the tendency for clinicians to overlook symptoms of mental disorders in people with an ID and attribute them as part of 'having an intellectual disability'[23, 24]. It can negatively affect the accuracy of clinicians' judgments about identifying associated mental disorders in people with both ID and mental disorder.

Disability services

Services and supports for people with disabilities provided by government and other agencies, to enable and assist people who have disabilities to fully participate in society and community life.

Family and carer(s)

This term is used to refer to persons that provide care and support to an individual with an ID and possible co-occurring mental health issue. Carers can include family, friends or professional workers and can be paid or unpaid. The role of the carer may vary over time according to the needs of the consumer and carer.

headspace

www.headspace.org.au

headspace provides a national coordinated focus on youth mental health and related drug and alcohol problems. It aims to improve service access for young people and ensures better coordination between services. The headspace model provides for holistic care in key areas – mental health, physical health, alcohol and other drug use, and social and vocational support. The model provides a service platform for, and entry point to, existing services by engaging a range of youth workers and mental health professionals, as well as referring young people to other appropriate services.

Intellectual disability (intellectual developmental disorder)

The term most commonly used in Australia to describe permanent impairment of general mental abilities that impact domains of adaptive functioning. An individual's cognitive impairment must begin during the developmental period (before the age of 18) and are diagnosed based on the severity of deficits in adaptive functioning. An ID is diagnosed using a combination of standardised intelligence tests, such as IQ scoring, and assessments of adaptive functioning. The severity of ID can be classified as mild, moderate, severe or profound. The DSM-5 uses the term 'intellectual disability' to replace the term 'mental retardation'. ID may co-occur with other developmental disorders and other mental disorders[1].

Learning disability

A term used to describe a significant learning problem in one or more academic areas. The term has been used extensively in the United Kingdom in relation to learning disability services, in which a major focus has been people with an ID. The definition of 'Learning Disability' as

defined in the Australian Commonwealth Disability Discrimination Act 1992 is 'A disorder or malfunction which results in the person learning differently from a person without the disorder or malfunction…'[58].

Medicare Local

www.medicarelocals.gov.au

Medicare Locals were established to plan and fund extra health services in communities across Australia. Medicare Locals were created to ensure decisions about health services could be made by local communities in line with local needs. Medicare Locals aim to work with primary health care providers to ensure people can access effective primary health care services.

Mental disorder

A "syndrome characterised by clinically significant disturbance in an individual's cognition, emotional regulation, or behaviour that reflects a dysfunction in the psychological, biological or developmental processes underlying mental functioning" (*American Psychiatric Association*, 2013, p. 20)[1]. Examples of such conditions include mood disorders, schizophrenia, anxiety and personality disorders.

Mental health services

Services with the primary function to provide clinical treatment, rehabilitation or community support for people affected by mental illness and/or their families, carers and support networks. Mental health services are provided by organisations operating in both the government and non-government sectors. *Adapted from the Mental Health Statement of Rights and Responsibilities (2012)*[38].

Mental illness

A clinically significant disturbance of mood or thought that can affect behaviour and cause distress for the person or those around them. Mental illnesses may impact the person's ability to function normally and can interfere with a person's cognitive, emotional and social abilities.

National Disability Insurance Scheme

www.ndis.gov.au

National Disability Insurance Agency is the agency that will administer the National Disability Insurance Scheme as under the National Disability Insurance Scheme Act 2013. It offers a new way of providing community linking and individualised support for people with permanent and significant disability, their families and carers.

Primary health care

Essential health care made universally accessible to individuals and families in the community. It is usually the first level of contact that people have with the health system. Primary health care can involve health promotion, prevention, treatment and rehabilitation. It includes many health professionals, who respond at a local level to their communities' needs. These may include physicians, nurses, midwives, community workers, and others. Primary health care should be sustained by integrated, functional and mutually supportive referral systems towards the improvement of comprehensive health care for all. *Adapted from the WHO Alma-Ata Declaration (1978)*[59].

Telehealth

www.medicareaustralia.gov.au/provider/ incentives/telehealth

An expanding sector of healthcare involving the use of telecommunication tools. A wide range of techniques fall into this sector, including the administrative, preventative, consultative and curative aspects of healthcare. The communication technologies involved are similarly broad, ranging from telephones and e-mail to robotic surgery performed at a distance. Telehealth aims to remove some of the barriers to accessing medical services to individuals who live in rural and remote areas or have difficulty getting to a specialist.

Artwork by Rhonda Browne, 2013, Miroma

Core Reference Group

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

CRG Member	Position	Organisation / Professional Association and Interest Group
Ms Andrea Ching	Project Manager The Guide	Department of Developmental Disability Neuropsychiatry, School of Psychiatry University of New South Wales
Dr Catherine Franklin	Senior Lecturer and Consultant Psychiatrist	Queensland Centre for Intellectual and Developmental Disability at the University of Queensland
Dr Linda Goddard	President	Professional Association of Nurses in Developmental Disability Australia
Dr Nick Hagiliassis	Psychologist and Committee member	Australasian Society for Intellectual Disability
Prof Nick Lennox	President	Australian Association of Developmental Disability Medicine
A/Prof Keith McVilly	Convenor, Special Interest Group on People with Intellectual and Other Developmental Disabilities	Australian Psychological Society
Mr Andrew Pridding	Member, Mental Health Nurse Practitioner	Australian College of Mental Health Nurses
Mr Jim Simpson	Senior Advocate	NSW Council of Intellectual Disability
Dr Jennifer Torr	Chair, Special Interest Group in the Psychiatry of Intellectual and Developmental Disabilities	Royal Australian and New Zealand College of Psychiatrists
A/Prof Julian Trollor	Chair, Core Reference Group	Chair Intellectual Disability Mental Health, School of Psychiatry University of New South Wales

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.

Adaptive Behavior Assessment System – Second Edition, various versions (ABAS–II)	**www.pearsonclinical.com.au/ productdetails/21** 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/rcpp/1901242994.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/spppm/research/devpsych/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-ID): A Textbook of Diagnosis of Mental Disorders in Persons with Intellectual Disability	**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.
DC-LD: Diagnostic Criteria for Psychiatric Disorders for use with Adults with Learning Disabilities	**www.rcpsych.ac.uk/publications/collegereports/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.

Inventory for Client and Agency Planning (ICAP)	**icaptool.com** The ICAP is a widely used assessment of adaptive behaviour that can be used in a number of settings, including in children and adults with an ID. It assists the gathering of detailed information about adaptive and maladaptive behaviours and support needs.
PAS-ADD Suite of Mental Health Assessments	**www.pas-add.com** Psychiatric Assessment Schedules for Adults with Developmental Disabilities – a set of mental health assessments for people with an ID that have been in continuous development. The suite includes the PAS-ADD Checklist, Mini PAS-ADD, ChA-PAS and the PAS-ADD Clinical Interview.
Scales of Independent Behavior – Revised (SIB-R)	**www.riversidepublishing.com/products/sibr/ index.html** The SIB-R is a comprehensive, norm-referenced assessment of adaptive and maladaptive behaviour.
Vineland Adaptive Behavior Scales (Vineland-II)	**www.pearsonclinical.com.au/ productdetails/244** Vineland-II is a measure of personal and social skills required for everyday living.

APPENDIX 2: EXAMPLES OF MODELS OF BEST PRACTICE

To date, there is no conclusive evidence to support a superior model of base practice for the delivery of mental health care for people with an ID. However, there are a series of reports, trials and studies which have generated positive feedback from clinicians, staff, carers and service users.

The various service models found to be beneficial have several factors in common, including the use of reliable diagnostic assessment tools and procedures, participation and collaboration of a multidisciplinary team, training of caregivers in the treatment plan, continued care from inpatient to outpatient stage, monitoring of the individual following treatment, and the use of a multi-system treatment approach[4].

A selection of best practice models and strategies are described below.

Evidence-based guidelines to reduce the need for restrictive practices in the disability sector

https://www.psychology.org.au/Assets/ Files/Restrictive-Practices-Guidelines-for- Psychologists.pdf

A practice guide prepared by the Australian Psychological Society (APS) to reduce restrictive practices in the disability sector by increasing the use of positive behaviour support programs. The reduction of restrictive practices has relevance across a range of sectors including rehabilitation, mental health, forensic, juvenile and aged care settings to facilitate interdisciplinary collaboration to occur and to support systemic improvements

Mental Health Service for People with Intellectual Disability

www.health.act.gov.au/c/health?a=sp&pid=13 16133581&site=51117&servicecategory=12

The ACT Mental Health Service for People with Intellectual Disability is a joint initiative between Mental Health ACT and Disability ACT. It is a specialist, cross-agency, consultation liaison service providing comprehensive clinical assessment and psychiatric treatment to consumers with an ID and mental illness. The team is co-located with Disability ACT and provides mental health expertise, training and education to community professionals and carers assisting people with an ID and a mental illness. This multidisciplinary service collaborates with treating practitioners, families, carers and other relevant agencies.

Meeting the Mental Health Needs of Adults with a Mild Learning Disability – Royal College of Psychiatry United Kingdom

www.rcpsych.ac.uk/files/pdfversion/cr115. pdf

Principles of normalisation and Government policy in the United Kingdom state that, wherever possible, people with an ID should use mainstream mental health services. However, these lack the resources, skills and expertise to manage this group of patients. Recommendations are made within the report to facilitate a collaborative system of care for this group of patients.
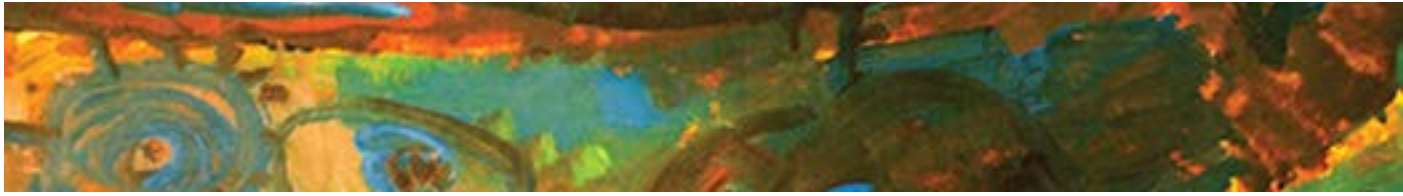
Meeting the health needs of people with learning disabilities – Royal College of Nursing guidance for nursing staff – United Kingdom

www.rcn.org.uk/__data/assets/pdf_file/0004/78691/003024.pdf

This guide has been developed in the United Kingdom to support registered nurses and nursing students in primary and secondary care, who are trained in fields other than ID, to deliver high quality health care to people with an ID. It highlights the specific health needs of people with learning disabilities, supports staff in making their services more accessible, and includes sources of further information. While this guide is aimed at nurses who may find themselves working with adults with an ID, those working with children may also find it useful.

Models of Service Provision to Adults with an Intellectual Disability with Co-existing Mental Illness – The University of Queensland

www.som.uq.edu.au/media/197709/sand_in_society.pdf

This report aims to enhance the quality of life of adults with a dual diagnosis within the community through improved access to appropriate services, and better coordination of services to these clients across government agencies and between government and non-government services.

Multiple and Complex Needs Initiative (MACNI)

www.dhs.vic.gov.au/about-the-department/plans,-programs-and-projects/projects-and-initiatives/cross-departmental-projects-and-initiatives/multiple-and-complex-needs-initiative

MACNI is a shared service across the Department of Human Services and the Department of Health in partnership with the Department of Justice Victoria. The initiative is a specialist service for people identified as having multiple and complex needs, including those with combinations of mental illness, substance abuse issues, intellectual impairment, acquired brain injury and forensic issues. These individuals can pose a risk to themselves and to the community. MACNI provides an effective and co-ordinated approach to supporting individuals so that they can achieve stability in health, housing, social connection and safety, and be linked back into comprehensive ongoing support.

Proposed model for the delivery of a mental health service to people with intellectual disability – Irish College of Psychiatrists, Dublin

www.rcpsych.ac.uk/files/pdfversion/op58.pdf

A proposed strategy with a series of comprehensive recommendations for the development of quality mental health services for people with an ID and their families. Included in the strategy is the establishment of multidisciplinary Intellectual Disability Teams led by a consultant psychiatrist with appropriate training in adult psychiatry and developmental/intellectual disability psychiatry. Other members of the team include psychologists, nurses, social workers, GPs, occupational therapists and speech and language therapists. The multidisciplinary team would offer treatment in a range of settings.

Reasonably Adjusted? Mental Health Services and Support for People with Autism and People with Learning Disabilities – United Kingdom

www.ndti.org.uk/uploads/files/NHS_Confederation_report_Submitted_version.pdf

The Equality Act 2010, United Kingdom expects mental health services to end discrimination against people with learning disabilities by making reasonable adjustments to their ways of working. The National Health Service UK commissioned a report to 'clarify and embed into practice reasonable adjustments for people with autism and people with learning disabilities in mainstream mental health services.' The report includes a number of practical examples, initiatives and recommendations for making mental health services more accessible.

Valuing People Now – United Kingdom

webarchive.nationalarchives.gov.uk/ 20110601212422/http:/www.valuingpeoplenow.dh.gov.uk

Valuing People Now is a cross government strategy from the United Kingdom. It asserts that all people with a learning disability are people first with the right to lead their lives like any other individual. It covers all aspects of life, including health, housing, paid employment, personalisation, transition, advocacy and relationships and utilises a multidisciplinary person-centred approach.

Victorian Dual Disability Service (VDDS)

www.svhm.org.au/services/VictorianDual DisabilityService
VDDS is a mental health service for people with an ID. VDDS works with specialist mental health services in Victoria to assess, treat and manage people with a dual disability. The service also delivers workshops and training for mental health professional development.

APPENDIX 3: TOOLS AND RESOURCES FOR CONSUMERS, FAMILY AND CARERS

Carer Depression Checklist

www.cddh.monash.org/research/depression
This checklist is for use by carers to be completed on behalf of adults who are unable to report their own feelings or symptoms because of severe communication impairment. It provides carers with a means of ensuring they have noted and recorded the information that is needed by a medical practitioner to decide whether a person with an ID may have depression or a mental health problem.

Electronic health record – the Personally Controlled Electronic Health Record (eHealth record)

www.ehealth.gov.au
An eHealth record is a secure online summary of an individual's key health information. The individual and their Authorised Representatives control what goes into it, and who is allowed to access it. Patients and their authorised healthcare providers can access it online whenever it is needed, from wherever they are. An eHealth record allows authorised doctors, hospitals and other healthcare providers to view and share their patient's health information. It aims to support better co-ordinated care where a patient is attending a number of health care providers.

Green Light Toolkit – Foundation for People with Learning Disabilities – United Kingdom

www.learningdisabilities.org.uk/content/ assets/pdf/publications/green-light.pdf
Green Light is a toolkit produced in the United Kingdom for improving mental health support services for people with learning disabilities. It describes what good mental health support service for people with learning disabilities should look like, and provides a standard to which local services can be compared. The toolkit is for people with mental health problems who have a learning disability, their carer(s), clinicians, commissioners, managers and staff in mental health, learning disability and primary care services.

Guide to Mental Health for Families and Carers of People with Intellectual Disabilities

www.jkp.com/catalogue/ book/9781843102779
This guide serves as a comprehensive introduction for carers to mental health problems. It outlines a range of signs and symptoms of mental health problems that can affect people with an ID. This resource was written with advice from carers and people with an ID in the United Kingdom who use mental health services.

NSW Council for Intellectual Disability – Fact Sheets

www.nswcid.org.au/standard-english/se- pages/fact-sheets.html
The NSW Council for Intellectual Disability has a series of fact sheets which provide information about a range of health issues important to people with an ID.

Parenting with an intellectual disability – Raising children network

raisingchildren.net.au/articles/parenting_ with_an_intellectual_disability.html
For parents, it can be a lack of suitable support services rather than the disability that can make it difficult to cope. This resource contains experiences from parents and provides information about the challenges facing parents who have an ID.

Personal Health Records for People with Developmental Disability

www.cddh.monash.org/products-resources/personal-health-records.html

A Personal Health Record (PHR) can be an effective tool in facilitating health management for people who have chronic or complex health problems. The PHR provides a comprehensive health record that is owned and held by the patients themselves and can aid in conveying important information to a new doctor.

APPENDIX 4: ADVOCACY SERVICES AND GUARDIANSHIP

Australian Guardianship and Administration Council (AGAC)

www.agac.org.au

The AGAC site provides information about member organisations and their role in protecting adults in Australia who have a disability that impairs their capacity to make personal or financial decisions. Public Advocates and Guardians seek to promote the best interests of persons with a decision-making disability and to protect them from abuse, neglect or exploitation.

Intellectual Disability Rights Service

www.idrs.org.au/home/index.php#sthash.d6U0m994.dpbs

The Intellectual Disability Rights Service (IDRS) is a specialist legal advocacy service for people with an ID in New South Wales. IDRS works with and for people with an ID to exercise and advance their rights.

National Council on Intellectual Disability (NCID)

www.ncid.org.au

The NCID is a recognised national peak body with the single focus on ID. Their actions and priorities centre on issues that affect the lives of people with an ID and their families and to safeguard the rights of people with an ID.

NSW Council of Intellectual Disability (NSWCID)	**www.nswcid.org.au** NSWCID is a peak body representing the rights and interest of people with an ID in NSW. The Council provides policy advice, systemic advocacy, community education, and information provision and dissemination.
National Disability Advocacy Agencies funded by the Commonwealth (by State or Territory)	**www.fahcsia.gov.au/our-responsibilities/ disability-and-carers/program- services/for-people-with-disability/ national-disability-advocacy-program/ models-of-disability-advocacy/national- disability-advocacy-agencies-funded-by- the-commonwealth-by-state-or-territory** This website provides a list of National Disability Advocacy Agencies funded by the Commonwealth Government.
Reinforce – Self advocacy	**www.reinforce.org.au** Reinforce is a self-advocacy organisation for people with an ID. Reinforce assists and encourages independence and promotes the rights of people with an ID.

APPENDIX 5: PROFESSIONAL ASSOCIATIONS AND INTEREST GROUPS

Australasian Society for Intellectual Disability (ASID)	**www.asid.asn.au** ASID aims to improve the quality of life for people with an ID by linking research to practice, with membership across Australia and New Zealand.
Association of Developmental Disability Medicine (AADDM)	**ausaddm.wordpress.com/home** The AADDM was formed as a network of doctors with an interest in pursuing improvement of the health status of people with intellectual and developmental disability (DD). The organisation focuses on the professional development of its members and their clinical colleagues, and political advocacy.

American Association on Intellectual and Developmental Disabilities (AAIDD)

aaidd.org/home

AAIDD promotes progressive policies, sound research, effective practices, and universal human rights for people with intellectual and developmental disabilities. AAIDD has been providing leadership in the field of intellectual and developmental disabilities through education, producing publications and influencing policy.

Australian Psychological Society Interest Group: People with Intellectual and/or Developmental Disability and Psychology

www.groups.psychology.org.au/piddp

An interest group under the Australian Psychological Society which aims to facilitate a national forum for discussion and information sharing and promote high standards in professional development and the practice of psychology in support of people with intellectual and other developmental disabilities. The interest group advocates for best practice in support of people with intellectual and other developmental disabilities, their families and support services.

National Association for the Dually Diagnosed (NADD)

thenadd.org

Based in the United State of America, NADD is a not-for-profit membership association established for professionals, care providers and families to promote understanding of and services for individuals who have developmental disabilities and mental health needs. The mission of NADD is to advance mental wellness for persons with developmental disabilities through the promotion of excellence in mental health care.

National Council on Intellectual Disability (NCID)

www.ncid.org.au

The NCID is a recognised national peak body focused on ID. Their actions and priorities centre on issues that affect the lives of people with an ID and their families, and to safeguard the rights of people with an ID.

Neurodevelopmental and Behavioural Paediatric Society of Australia (NBPSA)

nbpsa.org

The NBPSA website aims to provide a central place for information for patients and practitioners with an interest in neurodevelopmental and behavioural paediatric disorders. It provides a range of information including downloadable patient information documents, topical discussions, useful links and a searchable specialist section.

The Professional Association of Nurses in Developmental Disability Australia (PANDDA)

www.pandda.net/PANDDA/Home.html

PANDDA represents the professional interests of nurses who support people who have an intellectual developmental disability. PANDDA disseminates information and promotes communication between national and international organisations related to the field of developmental disability.

The Association of Psychologists in Developmental Disability Services (PsychDD)

www.psychdd.com.au

A professional interest group for psychologists who work in the developmental disability sector. PsychDD aims to support practitioners in their work with people with a disability and their families by providing opportunities for Continuing Professional Development. PsychDD advocates for their members, and also provides ongoing support and networking opportunities.

Royal Australian and New Zealand College of Psychiatrists (RANZCP) Special Interest Group in Psychiatry of Intellectual and Developmental Disabilities (SIGPIDD)

www.ranzcp.org/Membership/Subspecialty-groups/Interest-Groups/Intellectual-Developmental-Disabilities.aspx

The Special Interest Group in Psychiatry of Intellectual and Developmental Disabilities (SIGPIDD) is a RANZCP group that promotes the highest standards in clinical practice, training and research in the psychiatry of intellectual and developmental disabilities.

APPENDIX 6: RESEARCH AND ACADEMIC ORGANISATIONS

Centre for Developmental Disability Health Victoria (CDDHV)

www.cddh.monash.org

The CDDHV is an academic unit established by the Victorian State Government to improve health outcomes for people with developmental disabilities through a range of educational, research and clinical activities.

Centre for Disability Studies – The University of Sydney (CDS)

www.cds.med.usyd.edu.au

The CDS creates and disseminates knowledge to inform disability policy and practice and improve the lives of people with disabilities through research, teaching and clinical practice. CDS utilises a multi-disciplinary approach with research and teaching staff from a range of backgrounds including medicine, health sciences, education, psychology, speech pathology, physiotherapy, sociology and law.

Department of Developmental Disability Neuropsychiatry (3DN)

3dn.unsw.edu.au

3DN, University of New South Wales, supports and promotes the mental health needs of individuals with an ID through the education and training of health professionals, influencing policy and practice, and by conducting research in the field of intellectual and developmental disability mental health.

Estia Centre

www.slam.nhs.uk/about-us/clinical-academic-groups/behavioural-and-developmental/estia

The Estia Centre is a training and research centre based in the United Kingdom which aims to improve the care of people with an ID and additional mental health needs through evidence-based practice.

International Association for the Scientific Study of Intellectual and Developmental Disabilities (IASSIDD)	**iassid.org** IASSIDD is an interdisciplinary, non-government, world-wide organisation dedicated to the scientific study of ID. It promotes international research and the exchange of information in intellectual and developmental disabilities.
The Queensland Centre for Intellectual and Developmental Disability (QCIDD)	**www.som.uq.edu.au/research/research-centres/queensland-centre-for-intellectual-and-developmental-disability.aspx** QCIDD supports people with an ID through research, teaching and clinical activities. QCIDD is part of the School of Medicine at the University of Queensland.

APPENDIX 7: TRAINING AND EDUCATION

American Association on Intellectual and Developmental Disabilities E-Learning and Continuing Professional Education (AAIDD)	**aaidd.org/education/e-learning-and-ceus** AAIDD (see Professional Associations and Interest Groups) offers online continuing education and training opportunities to intellectual and developmental disability professionals.
British Institute of Learning Disabilities (BILD)	**www.bild.org.uk** Based in the United Kingdom, BILD uses its resources, membership information and networks to encourage the exchange of new ideas and good practice. BILD provides consultancy and, through support for the health and social care qualifications and training in the workplace, the institute helps support the development of staff and the organisations they work for. All of BILD's projects involve placing people with learning disabilities and family carers at the centre of the discussion into past experiences and future possibilities.

Centre for Developmental Disability Health Victoria (CDDHV)	**www.cddh.monash.org** CDDHV is working with the Royal Australian College of General Practitioners (RACGP) to develop online educational activities on the health and healthcare of people with a developmental disability. The GP learning website can be accessed at www.gplearning.com.au. CDDHV also offers undergraduate and postgraduate courses and training programs with training posts, with opportunities to participate in teaching and research. The Centre has produced an interactive learning resource - Healthcare Scenarios in Developmental Disability Medicine (CD-ROM) for health professionals.
Estia Centre – United Kingdom	**www.estiacentre.org** The Estia Centre offers a range of academic and training services to support adults with an ID and mental health needs through the development of a competent workforce from a variety of services. Estia offers academic programs and is planning e-learning courses open to anyone who supports people with learning disabilities.
General Medical Council Learning Disabilities - United Kingdom	**www.gmc-uk.org/learningdisabilities** This site aims to help doctors provide better care for people with learning disabilities by identifying the issues, highlighting patient perspectives and providing guidance in practice. Whilst the website has been produced for practitioners in the United Kingdom, there are various interactive resources that are able to be accessed and utilised internationally.
Information on Disability Employment Western Australia (ideaswa)	**www.ideaswa.net/training-manuals.html** ideaswa provides links to a series of downloadable resources that can be used as training material. Titles include *Caring Together, Challenging Behaviour Tip Sheets, Personal Care Support in Disability Services, Care Support Worker Training* and *Training provider/Service provider relationships.*

Intellectual Disability Mental Health e-Learning

www.idhealtheducation.edu.au
This e-Learning website has been developed by the Department of Developmental Disability Neuropsychiatry as a free training resource to improve mental health outcomes for people with an ID. Health professionals can work through learning modules at their own pace. The site is designed to be an interactive education resource for anyone with an interest in ID mental health.

Making Sense of Mental Health – United Kingdom

nbsbitesize.northampton.ac.uk/nass
Making Sense of Mental Health has been developed by NaSS (National Association of Independent and non-Maintained Special Schools) and the University of Northampton in the United Kingdom, to support staff working in special needs schools to understand the mental health of children and young people with complex needs. NaSS offers online training in identifying and recording mental health concerns and sharing these concerns in the work place.

Mental Health Professional Online Development (MHPOD)

www.mhpod.gov.au
MHPOD is an online professional development resource designed to support the implementation of the National Practice Standards for the Mental Health Workforce. MHPOD consists of topics based on the National Practice Standards including a topic with a focus on the co-occurrence of an intellectual or other developmental disability and mental illness.

The Queensland Centre for Intellectual and Developmental Disability (QCIDD)

www.som.uq.edu.au/research/research-centres/queensland-centre-for-intellectual-and-developmental-disability.aspx
QCIDD provides undergraduate and postgraduate education to health professions. QCIDD provides collaboration innovation around teaching through the Student doctors as Health Advocates Program (SHAP) where second year medical students have an opportunity to spend time with a person with an ID and attend their annual health check with the general practitioner. QCIDD also provides education to the community and disability sectors in the form of workshops, courses and conferences.

Victorian Dual Disability Service (VDDS)

www.svhm.org.au/services/VictorianDual DisabilityService
VDDS is a mental health service for people with an ID. VDDS works with specialist mental health services in Victoria to assess, treat and manage people with a dual disability. The service also delivers workshops and training for mental health professional development.

APPENDIX 8: BOOKS

Clinical Psychology and People with Intellectual Disabilities, 2nd Edition
Edited by Eric Emerson, Chris Hatton, Kate Dickson, Rupa Gone, Jo Bromley & Amanda Caine. Wiley (2012)

http://au.wiley.com/WileyCDA/WileyTitle/ productCd-0470029714.html
A comprehensive resource presenting current evidence-based practices and relevant clinical skills for working with people with an ID. Beneficial for mental health professionals and allied health staff including psychologists, psychiatrists, nurses and social workers.

Management Guidelines: Developmental Disability, Version 3, 2012
Therapeutic Guidelines Limited (2012)

www.tg.org.au/?sectionid=93

The guidelines aim to support medical practitioners in caring for people with developmental disability. It covers a broad range of stages – from birth to old age and assessment to long-term management. The guidelines have also been written to be accessible to people who are not professional health care workers.

Mental Health Services for Adults with Intellectual Disability: Strategies and Solutions
Edited by Nick Bouras & Geraldine Holt, Psychology Press (2010)

bjp.rcpsych.org/content/198/4/328.2.full

This book considers how mental health services have evolved over the past three decades to meet the needs of people with an ID, focusing on the ways that theories and policies have been applied to clinical practice.

Mental Health of Children and Adolescents with Intellectual and Developmental Disabilities:
A Framework for Professional Practice
Edited by David Dossetor, Donna White & Lesley Whatson, IP Communications Pty Ltd (2011)

www.silvereye.com.au/products. php?action=viewProduct&id=3428#. Ukjb84anrt8

A framework for clinicians who work with young people with intellectual and developmental disabilities and mental health problems and how their complex developmental, emotional, and behavioural needs might best be addressed. A model for how interdisciplinary and multi-agency collaboration and co-ordination might be facilitated is outlined, with an integration of biological, developmental, family, educational, social and cultural factors.

Positive Behaviour Support for People with Intellectual Disability: Evidence-based practice promoting quality of life
Edited by Keith McVilly. ASID (2003)

www.asid.asn.au/Publications/Books.aspx

This book presents a holistic, bio-psycho-social approach to behaviour support designed to promote quality of life for people with an ID. It provides evidence-based information to help the reader understand challenging behaviour, to develop and implement behaviour support plans, and monitor those plans to ensure their ongoing effectiveness. Guidance is provided on ethical and legal principles underpinning behaviour support.

*Psychiatric and Behavioural Disorders
in Intellectual and Developmental
Disabilities, Second Edition*
Edited by Nick Bouras & Geraldine Holt. Cambridge
University Press (2007)

**www.cambridge.org/us/academic/subjects/
medicine/mental-health-psychiatry-and-
clinical-psychology/psychiatric-and-
behavioural-disorders-intellectual-and-
developmental-disabilities-2nd-edition**
Drawing on clinical experience and research
findings, an international and multidisciplinary team
of experts brings together useful information on
mental health and behavioural problems of people
with intellectual and developmental disabilities.
The book highlights the principles behind clinical
practice for assessment, management and services
and offers practical advice for psychiatrists,
psychologists, nurses, therapists, social workers,
managers and service providers.

The Psychiatry of Intellectual Disability
Edited by Meera Roy, Ashok Roy & David Clark.
Radcliffe Publishing (2006)

bjp.rcpsych.org/content/190/2/182.full
A practical manual with guidelines for assessment
and multidisciplinary approaches.

*Seminars in the Psychiatry of Learning
Disabilities, Second Edition*
Edited by William Fraser & Michael Kerr. Royal
College of Psychiatrists Publications (2003)

**www.rcpsych.ac.uk/publications/books/
rcpp/1901242935.aspx**
A textbook that provides a comprehensive overview
of the psychiatry of ID. A resource for those
in specialist training, or those seeking a better
understanding of learning disabilities.

APPENDIX 9: OTHER RESOURCES

*Beyond speech alone: Guidelines for
practitioners providing counselling
services to clients with disabilities and
complex communication needs*

**www.scopevic.org.au/index.php/cms/
frontend/resource/id/128**
This publication provides guidelines for practitioners
providing counselling services to clients with
complex communication needs associated with a
disability.

Easy English Writing Style Guide

**www.scopevic.org.au/index.php/cms/
frontend/resource/id/1663/name/EE%20
Style%20Guide_2013_web.pdf**
This booklet provides a range of guidelines
to support the presentation of 'easy-to-read'
information in accessible reports, brochures and
flyers.

*Health Care in People with Intellectual
Disability – Guidelines for General
Practitioners*

**www.cds.med.usyd.edu.au/health-
publications/doc_download/6-health-
care-in-people-with-intellectual-disability-
guidelines-for-general-practitioners**
Produced by the Centre for Disability Studies,
these guidelines are designed to assist general
practitioners in providing comprehensive health
care to people with an ID. The guidelines provide
information about commonly occurring health
conditions that need to be screened for people
with an ID.

*ID and Ageing – A website on
intellectual disability and ageing*

www.idandageing.com
An educational resource for disability and
mental health workers, family and carers who
support people with an ID as they develop age
related health conditions with a range of useful
information and resources.

Intellectualdisability.info

www.intellectualdisability.info
Intellectualdisability.info provides an
understanding of ID and health for health care
professionals, who are required to support
equal access to their services for all people with
disabilities.

Intellectual Disability – Mental Health First Aid

www.mhfa.com.au/cms/wp-content/ uploads/2011/02/2nd_edition_id_manual_ dec10.pdf

This manual is for people working in human services to provide guidance on how to support people with an ID who are experiencing difficulties associated with mental health problems. There is also information in the manual that will assist those with little or no experience interacting with someone who has an ID. This manual builds on the information given in the Mental Health First Aid Manual, specifically taking into account the difficulties and needs of the person with an ID.

The Judith Trust – United Kingdom

www.judithtrust.org.uk

The Judith Trust, based in the United Kingdom, focuses its work on the problems faced by people who have both a learning disability and mental ill-health. The Judith Trust works for all those with both learning disability and mental ill-health to identify and close the gaps that they experience in their lives. The Trust seeks to ensure that the emotional, social and health needs and concerns of this population are understood and met. The Trust works to enable full integration and inclusion within society by developing new thinking, research and best practice.

Key Word Sign

www.newcastle.edu.au/research-centre/ special-education/key-word-sign-australia

Key Word Sign Australia was formerly known as Makaton Australia. Key Word Sign is the use of manual signs and natural gestures to support communication. It is used to encourage and support language development in children and adults with communication difficulties. Key Word Sign Australia supports children and adults with communication and language difficulties and provides resources to families, carers and professionals.

National Mental Health Recovery Framework 2013 – Guide for practitioners and providers	**http://www.ahmac.gov.au/cms_documents/ National%20Mental%20Health%20 Recovery%20Framework%202013-Guide- practitioners&providers.PDF** The Framework describes practice domains and key capabilities necessary for the mental health workforce in accordance with recovery-oriented principles. It provides guidance on tailoring recovery-oriented approaches to respond to the diversity of people with mental health issues. Chapter 10 'Keeping diversity in mind' includes guidance on supporting people with coexisting conditions and complex care needs with recognition of people with an ID.
Personalised Support	**www.centreforwelfarereform.org/library/by- date/personalised-support.html** This report describes how to provide support to people with the most complex needs or challenging behaviour, whether from brain injury, mental illness, dementia or a significant learning difficulty.
Your guide to: Communicating with people with a learning disability	**www.mencap.org.uk/sites/default/files/ documents/Communicating%20with%20 people_updated.pdf**
Your guide to: Communicating with people with profound and multiple learning disabilities	**www.plymouthhospitals.nhs.uk/ ourservices/clinicaldepartments/ learningdisability/Documents/ communicatingwithpeoplewithPMLD_a%20 guide.pdf** Produced by Mencap in the United Kingdom, these guides are designed to provide an introduction to communication, and the problems faced by someone with a learning disability. The guides also contain tips on how to be a better communicator, and how to assist someone with a learning disability to get their message across.

People who have an Intellectual Disability and the Criminal Justice System

www.villamanta.org.au/edit/documents/ People_with_ID_in_Criminal_Justice_System_ Project_Final.pdf

An educational tool and guide for those who come into contact with people with an ID who are involved in the criminal justice system. This guide aims to assist police, lawyers, advocates, Courts, Judges, Magistrates and corrections employees to better understand people who have an ID and to be aware of their rights and of the disadvantages they experience.

Practice Guidelines for the Assessment and Diagnosis of Mental Health Problems in Adults with Intellectual Disabilities

onlinelibrary.wiley.com/doi/10.1046/j.1365- 2788.2002.00421.x/full

These guidelines provide a summary of current knowledge regarding the assessment and diagnosis of specific psychiatric disorders in adults who have an ID based on clinical consensus.

United Nation Convention on the Rights of Persons with Disabilities

www.un.org/disabilities/convention/ conventionfull.shtml

The convention promotes, protects and ensures the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and promotes respect for their inherent dignity. Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which may hinder their full and effective participation in society on an equal basis with others. Australia ratified the convention on 17 July 2008. Under the convention, Australia is required to periodically submit a comprehensive report on measures taken to promote the rights and freedoms of those with disabilities.

Working with people with intellectual disabilities in healthcare settings – Fact Sheet

www.cddh.monash.org/assets/documents/ working-with-people-with-intellectual- disabilities-in-health-care.pdf

This fact sheet has been developed by the Centre for Developmental Disability Health Victoria to provide advice for health practitioners working with people with an ID including a series of strategies for providing good health care and communication tips.

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