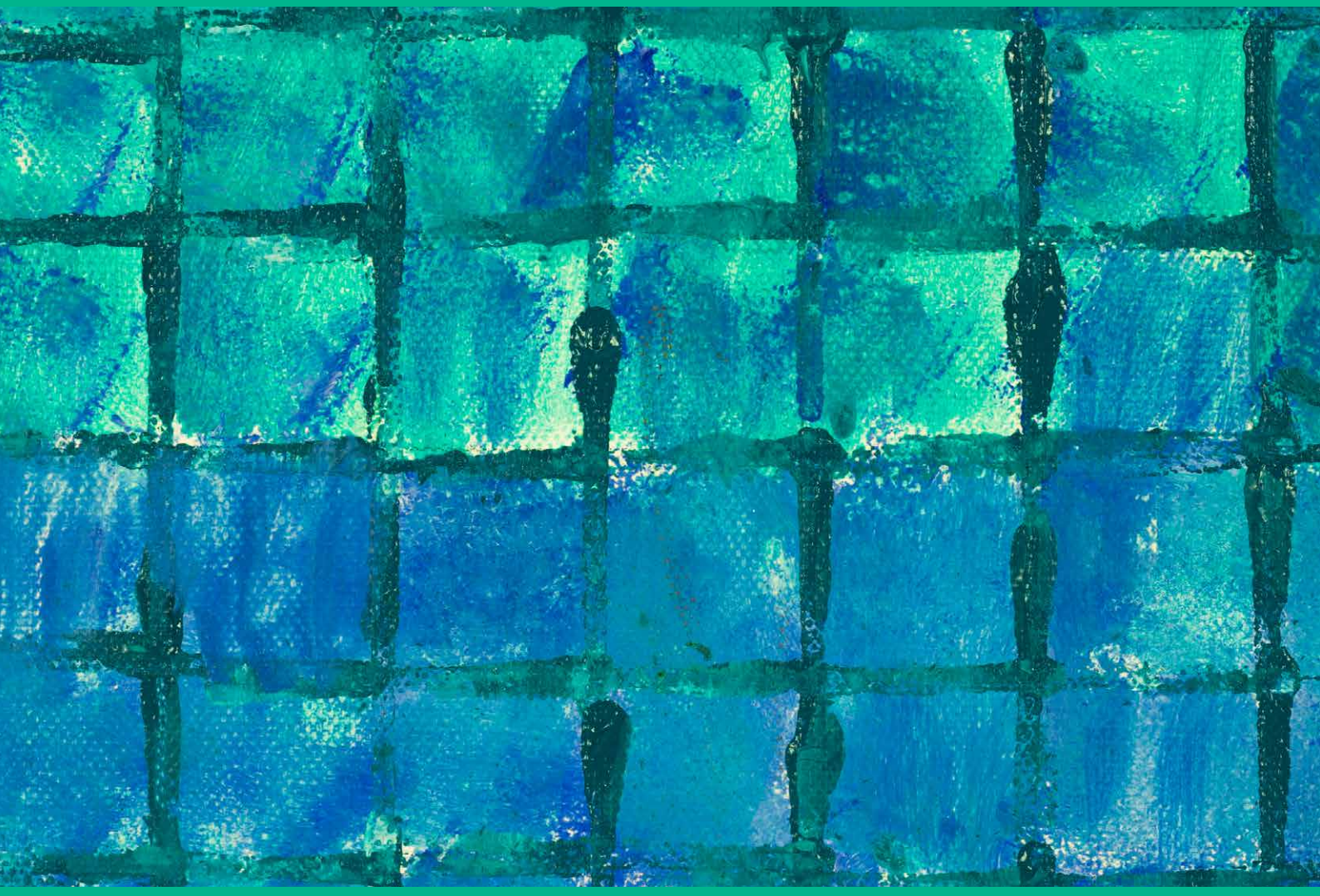
INTELLECTUAL DISABILITY MENTAL HEALTH CORE COMPETENCY FRAMEWORK:

A PRACTICAL TOOLKIT FOR MENTAL HEALTH PROFESSIONALS



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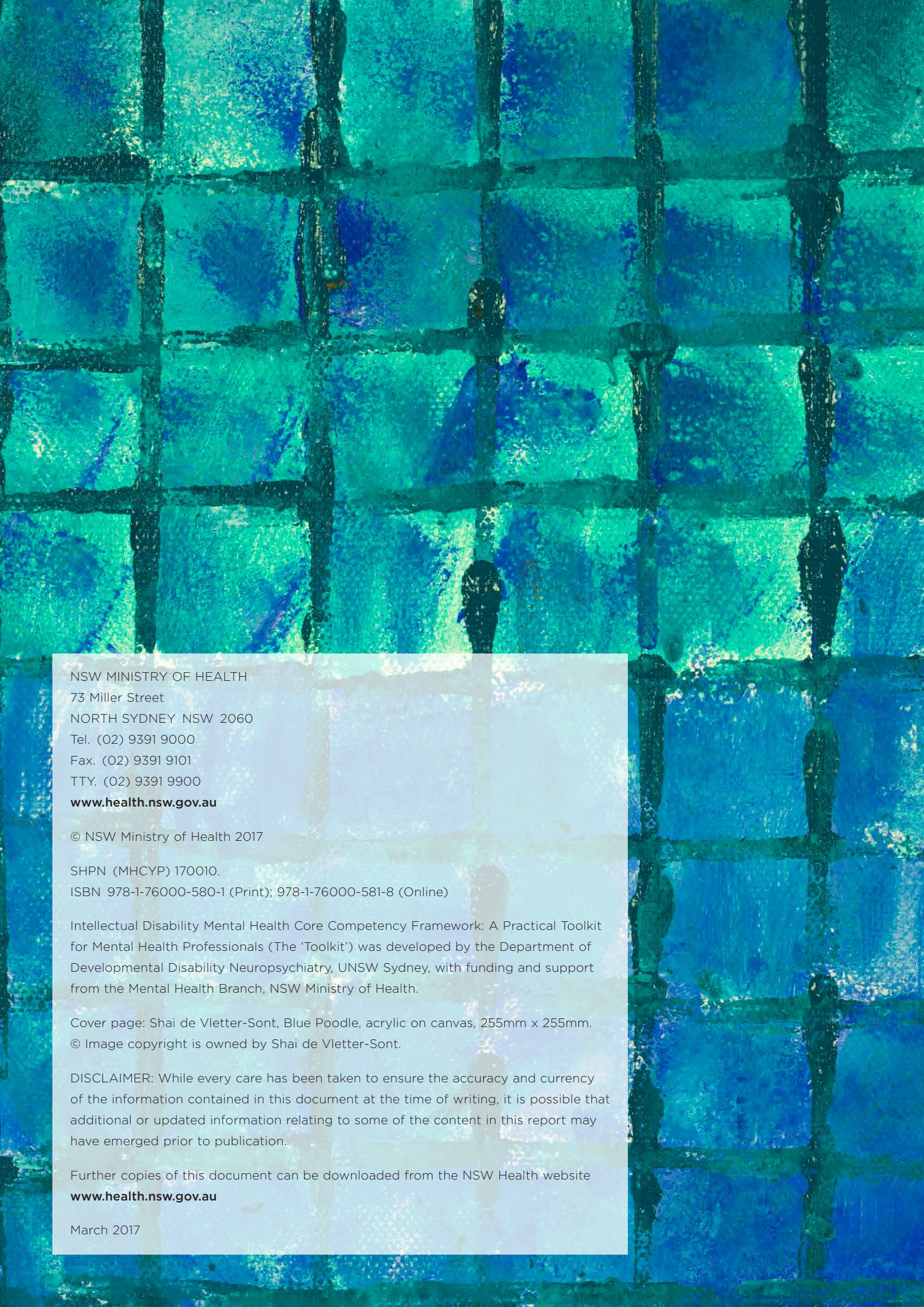

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March 2017

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Executive Summary

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Equitable and appropriate access to high quality mental health care for people with an intellectual disability is a priority for the NSW Ministry of Health, and is the responsibility of all professionals working in the public mental health sector.

Equitable and appropriate access to high quality mental health care for people with an intellectual disability is a priority for the NSW Ministry of Health, and is the responsibility of all professionals working in the public mental health sector. In partnership with the Chair of Intellectual Disability Mental Health (IDMH) at UNSW Sydney, the Mental Health Branch identified the need for an intellectual disability mental health core competency framework for mental health professionals working in the public health sector.

The Intellectual Disability Mental Health Core Competency Framework: A Manual for Mental Health Professionals (The 'Framework') was subsequently developed. The Framework describes the core attributes required by mental health professionals when working with people with an intellectual disability and co-occurring mental ill health across the age spectrum. It outlines what is important from the perspective of people with an intellectual disability, their families and support networks, and IDMH experts.

This accompanying Toolkit, developed by the Chair of IDMH in conjunction with a Project Advisory Group, will assist mental health professionals to develop the core competencies and improve their delivery of quality services to this population. Although the Framework and Toolkit were commissioned to strengthen the practice of public sector mental health professionals, they will also have relevancy for the broader workforce supporting people with an intellectual disability and mental ill health.

Making reasonable adjustments to clinical practice is achievable for all mental health professionals and is known to improve the experience of people with an intellectual disability and their families and support networks. The Toolkit supports mental health professionals to assess and respond to the mental health needs of people with an intellectual disability by providing practical advice on adjusting their clinical practice, recommending suitable assessment tools, relevant resources, education, and training materials. It will also assist in professional development planning. The Toolkit is highly recommended for all those seeking to improve the quality of service that individuals with an intellectual disability and co-occurring mental ill health, and their families and support networks, receive.

Acknowledgements

We wish to thank the Project Advisory Group for their generous sharing of expertise and time. We acknowledge the individuals who have contributed to the development of this Toolkit. We wish to make special mention of those who have provided the vignettes and information on appropriate assessment tools.

The artwork in this document has been created by people living with disability. Works have been created by Mr Shai de Vletter-Sont, and also by artists from Studio A. Studio A is an independent, not for profit organisation that provides creative programs to adults with disability. For more information visit www.studioa.org.au.

We thank Mr Shai de Vletter-Sont and Studio A for allowing these works to be included in the Toolkit.

studio A

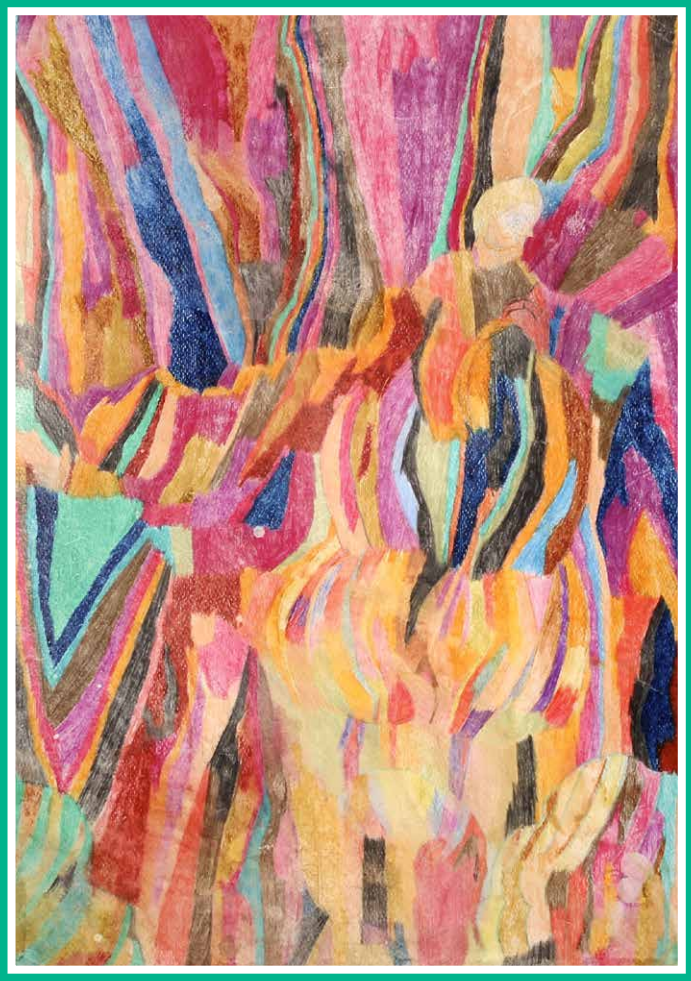
A note on the language used in this toolkit

The language used to describe a people shapes beliefs and ideas held about them. This Toolkit uses person first language. Person first language reminds us that we are talking about individuals who have, or live with a disability, and/or mental ill health.

The language used in this document also reflects the whole-of life approach of this Toolkit and current best practice for communicating about and with a person with a disability or mental ill health.

Particular examples of the language that will be used include:

- Patients/Client(s) will be referred to as a person or people with an intellectual disability or person or people with an intellectual disability and co-occurring mental ill health
- Carer referred to as family and support persons/networks
- Parent or other family members referred to as family.



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Introduction

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Individuals with an intellectual disability experience higher rates of mental disorders than the general population, with common mental disorders being at least two to three times more likely in people with an intellectual disability.

Introduction to the toolkit

Individuals with an intellectual disability experience higher rates of mental disorders than the general population, with common mental disorders being at least two to three times more likely in people with an intellectual disability. [1-5] However, this population experiences considerable barriers that prevent them from participating in, and receiving quality mental health care. These barriers include a lack of specific services and workforce capacity in IDMH.

Mental health professionals have an opportunity to make a considerable difference to people with an intellectual disability who are experiencing mental ill health by:

- applying what they already know;
- adapting some current clinical practices; and
- building their core competencies in this area.

Some mental health professionals may have had limited access to education and training in the area of IDMH, and limited opportunities to work with this group. Therefore this Toolkit has been developed to provide mental health professionals with information about adapting clinical practices and accessing useful resources.

What are the aims and scope of this Toolkit?

This Toolkit aims to:

- provide practical information for mental health professionals to assist in the development of the core attributes described in the Framework and guidance on practical ways to adapt their practice;
- describe how mental health professionals can continue to improve their core competencies with links to resources that can support professional development; and
- outline how service managers can help to implement the Framework and Toolkit in their mainstream services (i.e. non-specialist IDMH services).

While the information in this Toolkit is not intended to be exhaustive, it provides a starting point for professionals to then seek out further information from the resources listed. In addition to mental health professionals, the Toolkit will also have relevancy for the broader workforce supporting people with intellectual disability and mental ill health.

Why is this Toolkit applicable to all mental health professionals?

All mental health professionals have a responsibility to provide quality mental health care to their clients, including those with an intellectual disability (see Article 25 of the United Nations Convention on the Rights of Persons with Disabilities). [6] This Toolkit, along with the Framework provides guidance and resources on the essential mental health knowledge and skills required to make sure that people with an intellectual disability and co-occurring mental ill health receive available, accessible, acceptable and quality mental health care (which is the basis of a rights-based approach to health services). The Toolkit may also enhance clinical practice with other groups of mental health service users such as people with communication or cognitive impairments.

The overarching clinical principles that should guide mental health services when supporting people with an intellectual disability and co-occurring mental ill health are outlined in Appendix B. These include:

- rights;
- inclusion;
- a person-centred approach;
- promoting independence;
- evidence-based practice
- recovery-orientated practice;
- strength-based practice;
- flexible practice,
- proactive practice; and
- multidisciplinary and cross agency practice.

How can I use this Toolkit?

Mental health professionals and service managers can use this Toolkit in a number of ways. It is designed to be used in conjunction with the Framework. It is also complementary to Accessible Mental Health Services for People with an Intellectual Disability – A Guide for Providers 'The Guide'. [7]

Mental health professionals

Mental health professionals can use this Toolkit to:

- make reasonable adjustments to their clinical practice to assist in improving the assessment and management of mental ill health in people with an intellectual disability; and
- access relevant resources, education, and training materials to assist in adjusting current clinical practice and developing new skills and knowledge in the area of IDMH.

In acknowledgement of the competing demands on mental health professionals' time, this Toolkit is divided into clear topics, which can be consulted when necessary at different stages of the assessment and treatment pathway (including Intake, Engagement, Assessment, Treatment and Transition).

For mental health staff seeking a comprehensive skill set for working with people with an intellectual disability, reviewing the entire document is highly recommended. Some staff may also find it useful to concurrently work through the modules in the Intellectual Disability Mental Health e-learning resource. This is a free interactive education resource that aims to assist mental health staff to gain knowledge and skills in the area of IDMH.

Service managers, service developers, and individuals responsible for quality improvement

Service managers, service developers, or individuals responsible for quality improvement frameworks could use this Toolkit:

- to consider ways to implement the Framework in their service;
- for the professional development of their staff;
- to inform education and training plans; and
- to guide recruitment of appropriately skilled mental health professionals.

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SECTION ONE

Practical information on adapting clinical practice

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Practical information on adapting clinical practice

This section provides introductory information on how mental health professionals can adapt their clinical practice to align with the attitudes, beliefs, values and approaches outlined in the Framework. It can be used in conjunction with the Self-assessment tool in that document.

1. Intake

1.1 Intake procedures

Adapting practice at the intake stage can help to achieve the core competencies described in section 7, *Intake* of the Framework.

Triage can be more complex for people with an intellectual disability and co-occurring mental ill health as there are limited resources (e.g. specialist IDMH services and mainstream mental health professionals with expertise in intellectual disability), and the responsibility for which services should provide care can be unclear (e.g. local community mental health services or disability services). As there are only pockets of expertise available and no specialist IDMH services uniformly available across the state, all mainstream services must ensure that they are equipped to triage people with an intellectual disability and mental health concerns.

Below are a number of considerations that can improve the intake process for people with an intellectual disability.

- It is important to speak with both the person with an intellectual disability and the referrer if possible; referrals are often organised by a third party (GP, relative, friend or paid support person). Ask about the needs and expectations of all parties to ensure your service is suitable for them.
- When speaking with the person with an intellectual disability for the first time, consider their communication needs and developmental capacity; allocate extra time during the intake process.

- Appreciate that the person with an intellectual disability and the referrer may not have a background in mental health, and therefore may not use the language commonly used within mental health services. Do not expect them to use such language.
- If a person presents with challenging behaviour, give due consideration to the cause of the behaviour. Do not automatically assume that the behaviour is related to the person's intellectual disability, but also explore mental health or other potential drivers.
- Determine if the person has a personal health record and utilise this.
- It is likely that the person referred has already had a number of assessments and accessed other services. It is important to access previous assessment notes and records where possible, with consent. This prevents extensive re-assessment and repeating a referral pathway that may not have been favourable for the individual in the past. Assess areas that may not have been covered in previous assessments.
- Intake may need to be completed over a period of time. That is, not all information may be available the first time that you contact the person or the referrer.
- Decisions on intake assessment may need to be based on longitudinal rather than cross sectional data. For example, instead of asking how the individual's sleep is currently (cross sectional), ask them how their sleep has been over the past two years, how it has changed in that time and how it is now in comparison to that period (longitudinal).
- Discuss the clinical pathway through your service, providing accessible information to the person with an intellectual disability, their family and support network, and their referrer.
- Determine if any additional assessments are required (e.g. a physical health assessment), and if so, refer the person to a suitable service.
- If the person is not suitable for your service at intake, inform the person and the referrer why they are not eligible and provide information on appropriate services.

It is recommended that local services are aware of and document their roles and responsibilities (see 'The Guide') and keep an up-to-date compendium of available specialised services, at a local, regional or state level.

Table 1 details information to collect or consider during the intake process. This list is not exhaustive, and will depend on the presenting individual and situation.

Table 1. INTAKE GUIDE

Area	Information to be collected
General information	• Personal details • Family/support person contact details • Communication preference (verbal/non-verbal) • Preferred language (interpreter required?) • Type of accommodation (lives independently, family home, group home etc.) • Referrer/who instigated contact with mental health services • General Practitioner details • Has the individual been seen previously at hospital/clinic? • Personal health record?
Capacity to consent	• Consider the person's capacity to consent and make decisions about their health care. • Do they have an appointed guardian? • How they are usually supported to make decisions, in particular decisions relating to their health care
Presenting issues	• Reason for referral • Presenting signs/symptoms • Are challenging behaviours present? • Duration of presenting problems • Any previous interventions for presenting issues? • Risks issues (is there a risk of self-harm or harm to others? Consider referral to area crisis mental health service if appropriate) • What the referrer would like you to help the person with an intellectual disability achieve
Past psychiatric history	• Past mental health issues • Any diagnoses given? • Treatment and hospitalisations
Medical history	• Past and current • Cause and level of intellectual disability (if known) • Drug and alcohol use • Current medications • Are other mental health/health/disability support professionals involved?
Social history and support network	• Social and family background • Educational history • Strengths and coping mechanisms • With appropriate consent, gain information on support professionals and wider support network – who are they, what are their roles, what are their opinions of the mental health status of the person, what have they observed?
Support needs	• Communication needs and preferences • Sensory and physical support needs
Preparing person for the next stage – what to bring if proceeding with intake	• Medication list • GP referral with results of complete physical examination and blood tests • Specialist reports • Brain scan results (films and reports) • Behaviour intervention plan or report from service psychologist/key worker • Discharge summaries from previous hospital admissions (if any) • Reports from other disability service assessments

1.2 Clinical pathways

Adapting practice by making clinical pathways clearer for people with an intellectual disability can help to achieve the Framework core competency *7.2 Demonstrates an awareness of, and is able to inform the person, their family and support networks of the clinical pathway through the service in a readily understood way and confirms that the information has been understood.*

Mental health services and professionals can improve access for people with an intellectual disability by identifying a clear clinical pathway through their services. A clinical pathway is a standardised management plan for an identified client group through a service. It outlines the process that should be followed at each stage of care from referral to discharge, including the required assessments, clinical interventions, milestones, timeframes and documentation. A clinical pathway should be evidence-based and where possible multidisciplinary. [8, 9]

Table 2 below identifies some questions to consider at each stage of care when developing an intellectual disability specific clinical pathway for services.

This can then be used to guide a person with an intellectual disability through the service from intake to discharge/transfer of care.

Clinical pathways may be extended by considering the following:

- designating IDMH clinical care coordinators within public mental health services to coordinate access, triage and referral to appropriate health and disability services;
- developing specific IDMH 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 also to community mental health services; [7, 10]
- developing systems for coordinated transition of people with an intellectual disability between mental health service providers at various transition points e.g. child – youth, youth – adult, adult – older person; [11, 12] and
- ensuring appropriate transfer and handover of health and care information with other individuals and services involved in the clinical pathway.

Table 2. CLINICAL PATHWAY CHECKLIST: Questions to consider when developing an intellectual disability specific clinical pathway for services

Stage	Questions
Referral	• What information is accessible to people with an intellectual disability and disability service providers regarding accessing the service? • What additional information should be documented for people with an intellectual disability at the point of referral? • Is there a standardised place to document if the person will need any special assistance (environmental modifications, communication aids etc.)?
Intake	• How do we modify our language and intake processes to meet the needs of people who do not have a background in mental health? • What information is accessible to people with an intellectual disability about the service's available treatments? • Is the person with an intellectual disability able to communicate verbally? If not, what other communication methods and tools are available to mental health professionals? • What other services and supports is the person accessing? • What needs to be documented? • What is the timeframe for intake? • Who do we refer the person to if they do not meet the eligibility criteria of our service?

Stage	Questions
Assessment	• Are our standard mental health assessment and outcome measures suitable for all people with an intellectual disability? • What intellectual disability specific assessment tools are available in mental health? When would these specific tools be required? • Is there capacity for multi-service assessment and what is the process for facilitating this? • Who else can I contact to receive information about the person to facilitate the assessment process? • What needs to be documented? • What is the timeframe for assessment? • What environments can assessment be undertaken in? • What steps should mental health professionals follow to determine if the person with an intellectual disability has capacity to provide consent for treatment?
Clinical case formulation/ multidisciplinary review	• What other local health professionals and services should participate in case formulation (conceptualisation of information on presenting problems obtained from intake/assessment) and review? • What is the timeframe for case formulation and subsequent case review for people with an intellectual disability? Is there any evidence to suggest review times should be different from people without intellectual disability? • If the current service is deemed not suitable, are there other services suitable for people with an intellectual disability within the organisation? What is the procedure for referral within the organisation and outside the organisation? • What needs to be documented?
Developing care plan/clinical Intervention	• What other services and supports is the person with an intellectual disability already accessing? • What other sectors should have a role in the person's care plan? • Who is responsible for each element of the intervention? • Are there any modifications that need to be made to deliver standard mental health interventions to someone with an intellectual disability? • How do we manage when there are conflicting opinions or content in care plans from different services? • What needs to be documented? • What is the timeframe for interventions? • Who has a copy of the care plan? • Does the person with an intellectual disability and their family and support network (where appropriate) have a copy of the care plan which has been prepared with them collaboratively and presented in a way that they can understand?
Discharge/ transition of care	• What other services and supports are available for people with an intellectual disability? • What are the procedures for coordinating a safe and effective transition between child, youth, adult, and older adult services? • What are the procedures for transfer of care to other services? • What needs to be documented? • Is there any additional information required in the transfer of care/discharge summary? • How do mental health professionals, family and support networks support the person with an intellectual disability during discharge-related transitions?

2. Engagement

The following section outlines ways people with an intellectual disability and their family and support networks can be engaged in the assessment, treatment, and transfer of care.

2.1 Common Clinical Competencies

Adapting general clinical practices can help to achieve the core competencies described in Section *6. Common Clinical Competencies* of the Framework.

Mental health professionals, especially those who have had no training in intellectual disability, often feel that they do not have the skills, knowledge or confidence necessary to treat people with an intellectual disability and co-occurring mental ill health. [13-16] However, only a very small percentage of people with an intellectual disability and co-occurring mental ill health receive specialised treatment.

This is due to a lack of resources, and where resources exist there can be long waiting times for referrals and consultations. Therefore, it is vital that there is increased workforce capacity and knowledge within the public mental health sector, Primary Health Networks, and private and not-for-profit mental health sector. This is important so that practitioners are able to assess and manage mental health conditions for those with an intellectual disability. [17]

The general principles of managing mental disorders in people with an intellectual disability mirror those used in the general population. While there is often added complexity for people with an intellectual disability, mental health professionals can learn to adapt their current clinical skills to work with this group. This helps to ensure that the person with an intellectual disability and their support network understands the clinical process and will receive quality mental health care. The impact of a person's intellectual impairment on their level of functioning and independence is contingent on various intrinsic and extrinsic factors e.g. the impact of impairment in communication may be reduced through the use of communication aids. Common clinical competencies that are required to work with people with an intellectual disability, and example adaptations are detailed in Table 3.

Table 3. CLINICAL ADAPTATIONS TO PRACTICE: Common clinical competencies and examples of practical adaptations to practice for working with people with an intellectual disability

Area	Clinical principle/skill	Example adaptations
Preparing	To encourage active engagement and participation, taking the time to prepare for working with the person by finding out about their strengths and support they require before starting treatment/ therapy	• When the individual is referred, determine an appropriate person to speak to (e.g. the individual, family member, friend or Disability Support Worker); ask about communication needs, sensory or mobility needs, level of anxiety around consultations, and strengths and abilities. • Consider what may help the individual attend the consultation (e.g. making the appointment in the afternoon if they are more alert at this time, or at a time when they can catch an accessible bus). • See section 2.2 Practical considerations for consultations
Capacity to consent	Assessing the capacity of the person to understand information, make decisions about their mental health care and provide informed consent	• Assess capacity to provide informed consent at different stages as capacity can change. • This includes how the individual receives, understands and remembers information, weighs up potential benefits and harms, gives reasoning, and conveys the choice to others. • See section 3.2 Informed consent and supported decision-making
Working with other decision makers	Identifying and working with legal guardians and other substitute decision makers	• This may be someone other than a parent or immediate family member, especially for adults and older adults. For example it may be a friend or unpaid support person. • The Public Guardian can be appointed if there is no suitable private individual. They would then make decisions regarding management of mental health treatment if the person is unable to do so themselves. • See section 3.2 Informed consent and supported decision-making, Appendix C Part 3. Legal and ethical issues, and http://www.publicguardian.justice.nsw.gov.au/

Area	Clinical principle/skill	Example adaptations
Confirming understanding	Confirming that the person and support network are aware of the clinical process, understand their right to be informed, and their right to participate in their mental health care	• Allow more time using communication methods preferred by the person with an intellectual disability, and provide information to support persons in ways it is readily accessible and simple to understand. • See section 2.3 Communicating effectively and 3. Assessment
Engaging all parties	Working with the person with an intellectual disability, their family and support network to maximise participation in the assessment process, care planning and intervention delivery	• Modify the length and number of assessment sessions (possibly in a different environment e.g. the person's home), • Talk directly to the person with an intellectual disability, and use non-jargon language with all parties. • There can be more individuals than usual involved in coordinating the care plan, so organise meetings to discuss with all relevant parties. Devise strategies to ensure the person's care plan is consistently used (e.g. if the person has more than one support person throughout the day). • Provide feedback to the individual and family and support network, and ask for their views on treatment plan progress. • Be able to work in situations where the support network do not all agree on the best approach to take. Discuss differing views and develop a management plan to trial. • See section 2.4 Involving support networks, 3. Assessment, and 4. Treatment.
Providing accessible information	Providing information to the person with an intellectual disability and their support network in a format that they can understand, and realising this format may be different for the individual, and support network	• Provide Easy read factsheets to people with an intellectual disability and information factsheets appropriate for family/support persons. • Work with everyone to ensure they understand the information. • See section 2.3 Communicating effectively.
Seeking specialist assistance	Identifying when support is required from other professionals or services, and actively seeking advice or a referral	• Seek support from a specialised ID health service, or use the RANZCP Find a Psychiatrist or APS Find a Psychologist search services. • See section 4.2 When and how to seek specialist assistance.

2.2 Practical considerations for consultations

Modifying practices and procedures before assessment and consultation sessions can help to develop core competency *8.3 Preparing for an assessment* in the Framework.

Considerations regarding the environment in which a consultation session is conducted with a person with an intellectual disability, and how it is conducted can facilitate the provision of quality care. These considerations are relevant across a number of settings including community, outpatient, emergency and inpatient services.

The following preparations and considerations can be beneficial to the assessment and management process.

Before the assessment:

- find out as much as possible about the person and their needs before the consultation from e.g. the referrer and support person if appropriate;
- find out about preferred communication methods and any aids to communication that are required (from individual, referrer or support person);
- find out about the person's level of independence, and whether any support persons will need to be involved at the assessment;
- book extra time for the assessment; more time may be needed to establish rapport and a double appointment, or two appointments may be needed;
- simplify appointment and referral letters by using Easy read, and making reminder phone calls;
- determine if the person has any special needs, such as mobility or sensory needs;
- if a consultation needs to take place in a clinic environment and it is known the individual is anxious about the appointment, a less formal visit to the consulting rooms can be organised beforehand. This may be an opportunity to bring in any relevant paperwork/health records, and if appropriate, ask for consent to access other relevant health records; and
- avoid cancelling consultations at short notice and where possible, prepare the person with an intellectual disability for changes (e.g. change of appointment time, therapist, environment or treatment modality).

During the assessment/consultation:

- if possible, the individual with an intellectual disability should be seen in a setting that is familiar to them e.g. their home, school or day centre;
- if required, consider the need to reduce stimulation by having the person wait in a quiet area and seeing the person with an intellectual disability in a suitable space for them so they are not unduly exposed to stressful environments and situations;
- try to avoid long waiting times in high stimulation environments; being punctual can assist in reducing the person's anxiety, which can improve the consultation process. If necessary, schedule buffer time before the consultation in case you are running behind schedule, or the first appointment of the day if appropriate;
- greet the person with an intellectual disability first, speaking to them directly; and
- if a family member or support person has accompanied the individual, check if the individual consents for them to sit in on the consultation, and for you to ask the third party about them. Check what the individual thinks about what the third party has said. Also check whether the individual would like to speak with you alone.

Vignette 1: Preparing for assessment

Ben is a 19 year old man with severe intellectual disability. He lives in a group home with a full time support person. Recently he has been increasingly agitated, fearful, and exhibiting behaviours such as turning his head and nodding when no one is there. His GP has been to see him and has referred him to a psychiatrist. The psychiatrist has the referral letter, which states that Ben is exhibiting signs of psychosis. When Ben's support person, Emily, calls to make an appointment, the psychiatrist also speaks with her and asks about Ben's communication needs. She says that Ben comprehends information best when short, simple phrases are used, and are augmented with picture symbols. While he has some verbal expressive language, Ben also uses signs and gestures. Emily, who will be accompanying Ben to his appointment, also mentions that he finds it distressing when there is noise around, and becomes anxious sitting in waiting rooms. The psychiatrist also asks about Ben's strengths, and what makes him feel more comfortable. Emily says that Ben becomes calmer and more verbal when discussing his favourite sport, car racing. To prepare for the assessment, the psychiatrist books a clinic room that is quiet, and leaves 15 minutes before the appointment clear so they can start on time and Ben will not have to wait. As Ben uses a wheelchair, she also arranges the clinic room for easy access. Finally, she ensures a picture board is available for use which has common symbols for concepts they may talk about like medication and sleep. Helped by this planning, the assessment goes well with Ben feeling less anxious than he did beforehand, and more able to engage in the consultation.

2.3 Communicating effectively

Modifying how you communicate with people with an intellectual disability can help develop the attributes described in core competency section *4. Communication* of the Framework.

For individuals with an intellectual disability, communication skills differ from person to person. Some people with mild intellectual disability will have the necessary expressive and receptive language skills to verbally participate in consultations. For people with moderate to severe levels of intellectual disability, they may use other methods besides speech as their primary communication method. [17] Individuals with an intellectual disability and health professionals identify poor communication as a significant barrier to effective health care. [18-20] For example, preventative health care information may not reach individuals with an intellectual disability, they may not understand how to take their medications, and may struggle to follow psychological therapy techniques.

Engage the individual first by speaking to the person referred directly, introducing yourself and your role, and explaining what type of service you provide in non-jargon language. Mental health professionals can conduct a brief assessment of the individual's communication skills towards the start of the session by asking some simple questions such as name, age, address and reason for their referral. Language and concepts should be kept simple, avoid using technical words, repeat questions as needed and speak at an appropriate speed. [17] In general, it is important to use a reflective approach when communicating, ensuring that your interpretation of the person's communication is accurate, and confirming that the person has understood what you were trying to convey. This may mean pausing longer than usual after asking a question or explaining something so the person has time to process what you have said. While open ended questions are generally preferable, if this is difficult for a person with an intellectual disability, offering a number of possible alternative answers can be beneficial. However, closed or direct questions can elicit incorrect answers as the individual may be trying to be agreeable by answering "yes".

Communication is more than just speech, and can be both verbal and non-verbal. For example, gesturing while talking, smiling or nodding, or showing people pictures. Some individuals will use augmentative and alternative communication methods, or AAC. AAC is a range of techniques and methods that can be used as an addition or alternative to speech; they can be unaided or aided (see Figure 1 and 2 below). [21]

A critical aspect of providing accessible services is providing accessible information to people with an intellectual disability and their family and support network regarding mental health, your service and treatment options. This includes use of AAC methods and provision of written information in Easy read and plain English formats.

If, with the use of AAC techniques, it is still difficult for the person with an intellectual disability to: understand; be understood; or if they have complex communication needs, it may be necessary for a support person to be involved. They can assist with interpretation of responses and provide additional information as needed.

Additional support may also be required from a communication specialist, such as a speech therapist.

See Resources section Communication tools for a list of useful communication tools and guides (such as picture symbols which were referred to in the above vignette).

Figure 1. Unaided augmentative and alternative communication methods

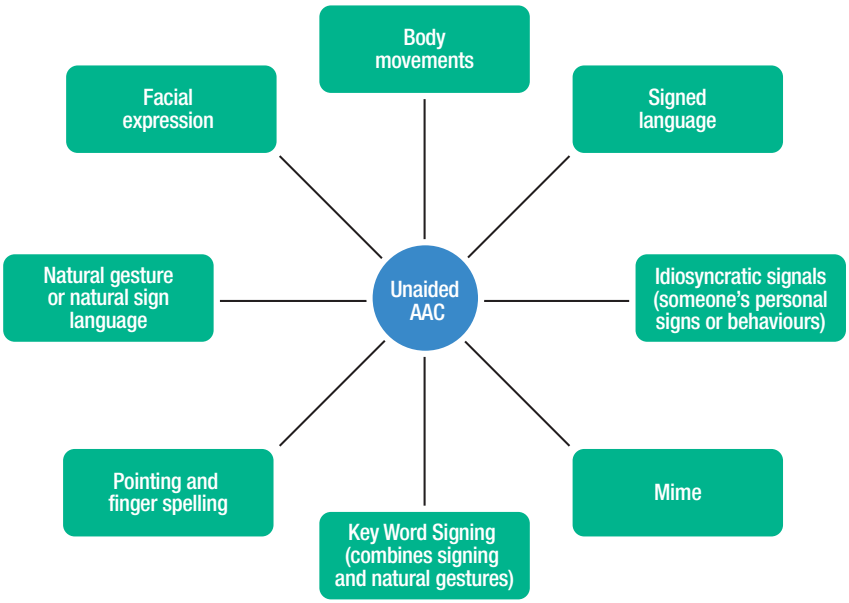
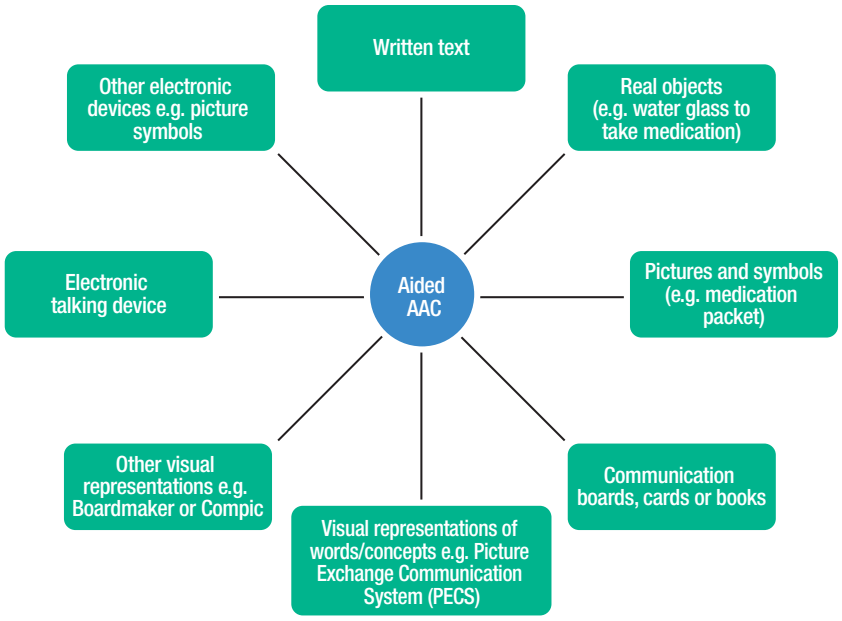


Figure 2. Aided augmentative and alternative communication methods



Vignette 2: Adjusting communication

Bridget is a 13 year old girl who lives with her family. She has a moderate to severe intellectual disability, autism spectrum disorder, acute anxiety and compulsive behaviour. She has limited communication skills, needs assistance with self-care, and has sleep and sensory processing difficulties. She likes to walk, cook and go swimming.

There is a long history of Bridget's challenging behaviours. These are associated with her autism, obsession with routines and activities, fear of novelty, narrowing of interests and activities, changes in sleep patterns and appetite, and an increasingly anxious and negative mood. This is compounded by her limited communication skills. A psychologist has recently started working with her and her family to develop strategies for managing her anxiety and mood.

Bridget is able to understand simple sentences and instructions but she needs time to process verbal information. She uses verbal language of 1-3 word phrases to ask questions and make choices, although these are often stereotypic and repetitive. She uses a fast speech rate which makes it difficult for others to understand. Her limited understanding of what people are trying to communicate increases her anxiety. Her psychologist thought it would be beneficial if she was assessed by a speech pathologist. Following the assessment, it was suggested that people communicating with her can assist her understanding of language by modifying their interactive style and providing augmentative communication supports.

Suggestions included:

- *Breaking complex instructions down into a sequence of single steps to help perform complex tasks.*
- *Using objects or photos to help Bridget to be more independent in completing everyday activities.*
- *Allowing her time to process information when she is asked a question or given an instruction. If she does not respond, to try repeating or rephrasing what has been said.*
- *Using **unaided supports** such as facial expressions, body movements, gestures, and pointing in order to add meaning to speech.*
- *In everyday conversations, for communication partners to use comments when talking to Bridget, rather than focusing on question/answer style interactions where a response is always expected (e.g. "there's a beautiful bird over there", rather than "can you see that beautiful bird over there?"). This is less stressful and provides opportunities to share experiences in order to make a connection.*

Bridget's family, support persons and psychologist used these techniques, and after a few months, significant improvement was observed in her anxiety. She appears to be far more settled as she has a better understanding of what people are communicating, and others are better able to understand what she is trying to convey.

2.4 Involving support networks

Developing knowledge and skills regarding how support networks can be involved in the assessment and treatment process builds core competencies described in Framework section *1. Responsible, Safe and Ethical Practice*, section *6. Common Clinical Competencies* and section *9. Mental Health Interventions and Care Planning.*

When appropriate, it is important for mental health professionals to engage family and support persons as collaborative partners in the assessment and management process, taking into account the preference of the person with an intellectual disability, their level of intellectual disability, and the severity of their mental health disorder. It is vital, where possible, to ask the person with an intellectual disability what their preference is regarding having a family member or a support person attend a consultation, and be part of the treatment process.

Identifying support networks

- Try to identify appropriate support persons before the first assessment consultation, either from the referrer, the person with an intellectual disability, or an individual who makes the appointment on their behalf.
- If a person does not have a support network, if required (and the person thinks it would be beneficial), actively assist them to find an independent support person e.g. a Disability Support Worker, or support person from a volunteer organisation.

The assessment

- The mental health professional should always address the person with an intellectual disability first, speaking directly to them, rather than the family member or support person.
- If it is established that the person with an intellectual disability is comfortable with the family member or support person sitting in on the assessment, the mental health professional should still direct their questions to the person with an intellectual disability in the first instance.
- To include the family member/support person in the assessment (if consent provided by the person with an intellectual disability), they can be asked to collate the person's medical history to bring to the assessment, and to discuss how they perceive the problem. Check in with the person with an intellectual disability to ask their thoughts on what has been said.

Supporting communication

- Depending on the communication strengths and needs of the individual with an intellectual disability, family and support persons can help the mental health professional and the person with an intellectual disability to understand each other. They can also help the mental health professional with guidance on what level of complexity the person with an intellectual disability will likely be able to understand. This may be important when discussing:
  - pharmacological treatment – advice about dosage, administration, therapeutic effects and side effects; and
  - psychosocial interventions – planning, adapting, and engaging in psychological therapies.
- Family and support persons can provide insight as to when the person with an intellectual disability may be becoming tired and is no longer engaging, or whether they may just be agreeing with what is being said because of fatigue.

Seeking information

- Family and support persons can provide valuable information relevant to assessment and diagnosis. Naturally, family members and support people vary greatly in their experience and skills in IDMH. They may describe general changes in wellbeing, rather than describing specific symptoms.
- After appropriate consent is sought, valuable information can be gained from conducting a detailed interview with the family member or support person who has known the individual on a long-term basis. [17] The mental health professional can:
  - ask for information on presenting symptoms and behaviours;
  - determine whether these symptoms are new or ongoing;
  - determine any potential precipitants in the individual's environment;
  - discuss underlying medical issues;
  - seek historical medical, social, psychological, and functioning information; and
  - identify the person with intellectual disability's personal strengths and coping strategies that have worked in the past to avoid only focusing on limitations and impairments. Strengths can include their interests, abilities, coping mechanisms, and their support network.

Vignette 3: Engaging support networks

Over the past 5 years Ada, a 66 year old woman with mild intellectual disability (due to meningitis as a child) has been experiencing cognitive decline. She has a history of transient ischemic attacks, and has been diagnosed with mild vascular dementia. She lives in a retirement village, where an independent support person comes 3 times per week to help her travel to appointments and the shops. Ada's younger brother is also involved with her care. Recently Ada's confusion has become worse, and her concentration, appetite and sleeping have also become a concern. While Ada's GP believes some symptoms could be due to dementia, he also suspects that Ada may be depressed, so refers her to a psychiatrist. With a reminder, Ada is able to make the appointment herself, and is asked whether anyone will accompany her. She says she'd like her brother to come. As part of the assessment, the psychiatrist asks about Ada's support network, and she mentions her brother, support person and the retirement village staff. She agrees that the psychiatrist can speak with them. After the assessment, and speaking to Ada's support network, the psychiatrist concludes that these recent symptoms indicate depression. She believes medication would be beneficial. While Ada still has the capacity to consent for many decisions, she has trouble understanding what effects the medication could have on her. She said that she would like to leave the decision to her brother (who is her 'person responsible'). He decides that it is in his sister's best interests to start the medication. Information about depression and taking the medication is provided to Ada in Easy read, with further factsheets provided to her brother and support person. The psychiatrist also discusses with Ada and her support network how they can assist her recovery. Retirement village staff ensure she is taking her medication until she gets into a routine, while Ada's brother and support person help by ensuring she does some exercise each day, continues to engage in daily activities and sees a psychologist regularly so she can learn ways to improve her mood.
All of these strategies result in reductions in her symptoms.

Providing information to support persons

- This can be a valuable way to enhance the person's treatment.
- Mental health professionals can provide psychoeducation, so that support persons can have a better understanding of the individual with an intellectual disability's mental health issues, and of their own role in the assessment and treatment process.
- Advice about effective interaction and communication with the person with an intellectual disability can be given, taking into account their mental health diagnosis. For example, strategies to encourage self-soothing or redirection for a person with anxiety, or advice about communicating empathically with the individual.
- Where a medical or psychiatric cause has been ruled out, information can be given on who to contact for a behavioural assessment and what will be involved.
- Family and support networks emphasise the importance of mental health professionals providing regular written and oral feedback about the person's progress.

The treatment process

- Take into account experience and training when discussing how the support person can assist with management and monitoring.
- Support persons can record information and monitor the person's progress, seeking unscheduled follow-ups if necessary. It is important to explain why this is important.
- Monitoring will be assisted by informing support persons about:
  - specific early warning signs;
  - acute mental health symptoms; and
  - possible steps to take.

- Review of the treatment process can be augmented by asking families and support persons to bring up-to-date information about the person's recent emotional state, appetite, sleep, behaviour, physical health and progress.
- Where appropriate, support people can also assist the person with an intellectual disability to complete any 'homework' exercises as a part of psychological therapies, and to take their medication at the correct times.

Creating a support plan for family and support persons

- A particularly useful way to help family and support persons to manage their contribution is to discuss a detailed support plan that includes:
  - a summary of agreed-upon steps;
  - details about monitoring and recording specific information about the person's response to treatment; and
  - medication details including dose, frequency, contra-indications and possible side effects.

2.5 Coordinating care across multidisciplinary services

Developing ways to coordinate care across multidisciplinary services for people with an intellectual disability helps to achieve the Framework core competencies *3.4 Works collaboratively with mainstream/specialist mental health services, health services and other support services to meet the needs of people with an intellectual disability* and those described in section *5. Partnership, Collaboration and Integration*.

People with an intellectual disability and co-occurring mental ill health can have multiple and diverse needs which are met by a range of intersecting services such as health, disability and education services. Therefore, their assessment, treatment and care requires a coordinated cross sector approach. To deliver best practice care and integrative interventions, active collaboration is required between service providers from various sectors, and service providers within each sector. To achieve improved outcomes for people with an intellectual disability, mental health professionals can work together with support services including those in:

- the disability sector;
- other health disciplines, including primary health care providers;
- advocacy;
- justice; and
- the education sector.

Coordinating care requires:

1. Identification of the person's existing supports and services, and
2. Gaining consent for sharing information across support networks and services.

Everyone must adhere to privacy legislation and local consent policies. Where possible, team leaders and service managers should identify or develop local protocols for collaboration between services. Their protocols facilitate cohesive and effective information exchange. This will enable a consistent understanding of the person's needs across service providers and can reduce the need for the person with an intellectual disability to repeat their story. To facilitate collaboration, use non-jargon terms so they will be understood by all services.

Sharing responsibility for a person's health care across different services can optimise their care and allow for efficient use of service resources (as long as there are clearly defined roles for each service provider). For example, mental health professionals could conduct joint assessments with other relevant services such as disability services, allowing sharing of expertise and increasing each party's understanding of the person's behaviours. In addition, ongoing multidisciplinary treatment planning and case review should occur. At such reviews, service providers can contribute their expertise to care plans and the role of each service can be clearly defined.

A GP usually coordinates physical and mental health care for people with an intellectual disability. Mental health professionals should consider contacting a person's GP to:

- collect information;
- conduct joint assessments;
- develop Mental Health Treatment Plans; and
- assist in the development of shared care plans.

Referrals or a transfer of care requires a thorough knowledge of the services available in the local area and matching these to the needs of the person with an intellectual disability. Communication between local services, developing partnerships with local services, and jointly coordinating discharge plans between services will optimise transition of care.

At the management level, services can support mental health professionals to work across sectors by:

- developing capacity for urgent referrals to mental health services from disability services, and vice versa;
- developing and implementing formal agreements and strategies between key services to enhance cross sector collaboration and coordinated case management;
- developing and implementing policies/procedures that enable co-management and coordination of mental health and disability services for people with an intellectual disability and co-occurring mental ill health;
- organising joint education and training initiatives that engage representatives from different components of the mental health service system (primary care, specialist, tertiary, cross disciplinary and private practice); [22]
- organising joint education and training initiatives that engage sectors relevant to the support of people with an intellectual disability (primarily those in disability, health, education and community services); and
- collaborating on the planning of services, considering the possibility of joint governance arrangements, shared locality, and shared responsibility for care.

Vignette 4: Collaborating across services

Isabella is a 35 year old woman with moderate intellectual disability who was diagnosed with Down syndrome at birth. She works part-time in a supermarket and lives in a group home with three other people. Over the past year, she has been experiencing depressed mood and anxiety, and has stopped hobbies she once enjoyed. Isabella has been taking medication prescribed by her psychiatrist, but her depression has suddenly worsened. As she is not responding to treatment and has begun to self-harm, her psychiatrist and GP suggest an admission to the local public mental health service. During inpatient assessment with a psychologist, it is learnt that Isabella used to attend a day program run by a local disability service, but she has since moved and it is too far to travel to. She says she misses her friends there, and that she has been feeling increasingly down ever since her move. Isabella provides consent for the psychologist to speak to her GP, psychiatrist, and disability support worker within her group home. Her GP highlights a history of recurrent depression triggered by environmental changes. The psychologist speaks with Isabella's support worker to find out about the impact of her depression on her daily routine. The psychologist believes that along with modified cognitive therapy, behavioural activation will be important as Isabella is doing very little during the day. After a 3 week admission, which included modified cognitive therapy and altering medication, Isabella reports she is starting to feel better. Isabella says she has always wanted to play tennis, so the psychologist organises contact with a local tennis club. The mental health service makes arrangements for her discharge. A visit by an OT is arranged to support Isabella to start carrying out daily tasks at home again. A daily activity list is developed, and discussed with Isabella's support worker. Mental health services transition her care back to her GP and private psychiatrist, and provide a discharge care plan which they discuss with Isabella and her support network. Isabella starts to help with cooking and daily tasks at home, and is going to the tennis club regularly where she is glad she has now made some new friends.

3. Assessment

This section describes: issues and practical advice for assessments with people with an intellectual disability, and information on informed consent and supported decision-making.

3.1 Assessment process

Modifying assessment practices and consulting further resources on assessing people with an intellectual disability can help to develop the core competencies described in Framework section *8. Assessment.*

Presentations of individuals with an intellectual disability can be somewhat different to people without an intellectual disability, and they may have different support needs. Assessing the mental health of individuals with an intellectual disability may require some modifications of standard approaches. A number of factors need to be considered in order to adequately assess mental health, including the presence and severity of an intellectual disability. For example, it may take additional time to collect information from a variety of sources and to resolve ambiguous presentations. It is important to conduct a multi-modal assessment, which covers biomedical, psychological and social domains, and involves input from a range of people.

Actively engage the person before asking more formal assessment questions. For example, asking how their day has been and what they have been doing lately, discussing their interests or hobbies, or what activities they have planned. For individuals who are non-verbal, other techniques may be more suitable, such as seeing if they would like to share any favourite photos or artwork. Once the individual is comfortable, more formal questions can start.

Recognising intellectual disability

- Intellectual disability varies widely in its severity and causes, and sometimes it is not obvious that a person has an intellectual disability.
- It is helpful in all health care settings to be able to recognise when someone may have an intellectual disability. While those with more severe disability will usually be accompanied by a support person, the majority of people have mild levels of impairment. Many will attend independently. Along with asking the person whether they have an intellectual disability, see Table 4 for other ways to determine whether someone may have an intellectual disability.
- Identifying that someone may have an intellectual disability can then help guide which support services they may require. Note some people with borderline or mild intellectual disability may not identify as having a disability, and they may not choose to disclose this (e.g. due to concerns about stigma, discrimination, or rejection of the concept of disability).

Assessment adaptations and considerations

- *Establishing baseline functioning*
  - While baseline functioning of someone without an intellectual disability is usually taken for granted, functioning and behaviour that is normal for a person with an intellectual disability varies significantly between individuals.
  - Their developmental level affects various aspects of their life, including communication style, self-regulation, and social interactions. These factors need to be taken into account when assessing the individual's mental health.

Table 4. Recognising intellectual disability (adapted from Hardy, Chaplin & Woodward, 2007) [23]

Activities	Recall	Life Experience
Do they:	**Can they remember:**	**Do they:**
• read • write • manage own money on a day-to-day basis • look after own personal care • cook • tell the time • have difficulty communicating (expression/comprehension)	• what you have said • significant things about themselves (such as their date of birth) • significant things about own environment (such as their home address) • when to do things (what time to get up, what time dinner is) • whether they struggled with school work	• attend a day program • live(d) in an institution or supported accommodation • have people who provide support with activities of daily living (such as support/ care workers, advocates, family members) • manage in social situations • receive a disability support pension • attend a special school or special class within a mainstream school, or did they used to attend one

- It is important to gather baseline information to determine whether the individual's current presentation is normal for them, or a sign of a mental disorder or physical illness. Mental health professionals can ask:
  - examples of activities the individual was able to do independently, and those they needed help with before the onset of current symptoms;
  - examples of things they enjoyed beforehand;
  - whether changes in mood, behaviour and functioning have been gradual or sudden, and when they began; and
  - if there has been any significant changes in their life (e.g. a change of support person, moving home).

- *Diagnostic overshadowing*
  - Behavioural change that is of concern to others is a common reason for presentation to mental health services in people with an intellectual disability. Diagnosis of a serious mental health issue can be missed if the behaviour is inappropriately attributed to the person's intellectual disability. This is termed 'diagnostic overshadowing'.
  - These factors can result in under-diagnosis and under-treatment of mental illness in people with an intellectual disability. Therefore it is always important to conduct an assessment, even if the mental health professional is unsure whether the presentation indicates a mental disorder.

- *Complexity and areas to assess*
  - Assessment and diagnosis can be complex as people with an intellectual disability have higher rates of comorbid medical/physical/sensory conditions, other disabilities, and polypharmacy.
  - Medical conditions and medications can have a significant impact on a person's psychological functioning, either by causing the psychiatric disorder (e.g. depression), or causing symptoms that may be mistaken for a psychiatric disorder (e.g. the side effects of medication may be mistaken for depression). [24] It is therefore important to take a detailed medical history and note any recent changes.
  - Gather information about the person's developmental history and cause of their intellectual disability if known. Particular syndromes that cause intellectual disability are associated with psychiatric and medical conditions, and this knowledge can assist mental health professionals in their assessment (e.g. Fragile-X syndrome is associated with anxiety, hyperactivity, hyper-arousal and autism spectrum disorders).
  - Further, certain genetic disorders that cause intellectual disability are associated with particular patterns of behaviour called behavioural phenotypes e.g. Prader-Willi syndrome is associated with poor impulse control, disturbance of satiety, obsessions, compulsions, and poor control over emotions such as anger. Becoming familiar with behavioural phenotypes can help clinicians interpret symptoms and formulate management plans. Information can be gathered from the individual with an intellectual disability's medical records, through research, and by consultation with specialists. Also see the Society for the Study of Behavioural Phenotypes website for more information http://www.ssbp.org.uk/syndromes.html
  - The individual's presentation may vary greatly in different contexts, so determining how the context influences their presentation can provide valuable information (is it worse in some contexts; not at all present in others e.g. at home, day programs, time spent with family?).
  - Collect assessment information on all relevant dimensions which may include developmental, biomedical, psychiatric, psychological/cognitive/social, adaptive behaviour, functional abilities, environmental, cultural, and educational history.
  - The individual is more likely to be experiencing challenges in multiple areas (e.g. physical health, social situations and housing), so identifying the causes of changes in behaviour and functioning is more complex.
  - To utilise a strengths-based approach, assess the individual's strengths including their abilities, interests, how they have coped with either mental ill health or challenges in the past, and their support network.

- *Atypical symptoms*
  - Symptoms of mental ill health are more likely to be atypical or behavioural in nature for people with an intellectual disability. Therefore, changes in behaviours should be investigated, rather than dismissed as 'disruptive' or a 'learned' behaviour.
- *Assessment tools*
  - Mental health professionals may use assessment tools to aid understanding of the person's presentation. A number of assessment tools have been developed or adapted for people with an intellectual disability (either for use with the person directly, or to assess behaviour observed by a third party). See Section Three – Assessment tools for a list of tools suitable for people with an intellectual disability.
- *Observation*
  - Observation can be an important tool when assessing an individual with an intellectual disability, especially someone with communication difficulties. Behaviour to observe includes how the individual interacts with you and others.
  - Using observational records such as sleep, weight and ABC charts are also valuable tools for others to observe behaviour when the mental health professional cannot.

Diagnosis

- As diagnosis relies heavily on verbal reports or representations of symptoms in psychiatric classification systems, using standard diagnostic criteria may be harder when assessing people with an intellectual disability who have difficulty communicating their symptoms. Different approaches can be used which rely more heavily on behavioural symptoms, such as using the adapted versions of ICD-10 and DSM criteria.
- A diagnosis should take into account that behaviour and cognitions that are thought to be due to mental illness may in fact be caused by pain, physical illness, medication side effects or stress.

Table 5 details some of the common errors made when a person with an intellectual disability presents with possible mental ill health.

After the assessment

- Consider repeating the assessment if appropriate (e.g. if the individual was tired, unwell, or presentation was ambiguous).
- With consent, speak to family, support persons and services e.g. health professionals the individual has seen, schools, disability services, and day groups about history and current presentation.
- Communicate with the person with an intellectual disability and family and support networks about the preliminary outcome of the assessment. Ask what they think about this feedback.
- Prepare all involved for what the treatment process will involve, and tell them about informed consent and the right to participate.

Table 5. How a person with an intellectual disability's presentation can be misinterpreted

The person *has* a mental disorder… but the mental health assessment *doesn't detect this*	The person *doesn't* have a mental disorder… but the mental health assessment *incorrectly concludes they do*
Signs of a mental disorder might be dismissed because they're interpreted as a part of the person's disability	The person may have habits or preferences or use coping strategies that seem unusual or bizarre – these could be incorrectly interpreted as signs of a mental disorder
Behaviour changes arising because of a mental disorder might be incorrectly viewed as: • behaviour the person has learned through reinforcement by a desired outcome • an attempt to gain attention or cause trouble	Signs that seem to indicate a mental disorder might actually be because of: • a medical condition • pain • a medication side effect • behavioural issues

Vignette 5: Assessment considerations

A clinical psychologist at a community mental health centre has an assessment with a 28 year old woman, Charlotte, who has Velocardiofacial (22q11.2 deletion) syndrome with moderate-severe intellectual disability. Referred by her GP, she has a history of ADHD, and various health problems. Her presenting symptoms as reported by her mother during a phone intake interview include increased agitation, fear, and disruptive behaviour, mostly outside the home. As she has had multiple assessments with psychiatrists, OTs, and disability professionals, the psychologist asks if Charlotte's mother can provide these reports to prevent extensive re-assessment. After researching the behavioural phenotype associated with Velocardiofacial syndrome and reviewing Charlotte's medical records, the psychologist keeps in mind that rates of anxiety and depression are elevated in individuals with this condition, and that 30% of individuals develop schizophrenia. When Charlotte and her mother arrive, the psychologist greets Charlotte first, and all agree that they will start the assessment together, and then each individual will talk with the psychologist separately. Picture cards and natural sign assist communication. The psychologist establishes Charlotte's baseline functioning, and despite her complex presentation, believes intellectual disability and ADHD are not the cause of her symptoms as her functioning has changed significantly in recent months. Appropriate assessment tools are used, including the Mood and Anxiety Semi-Structured Interview for Patients with Intellectual Disability. Two assessment sessions are needed, and in between the psychologist speaks with Charlotte's health professionals and her paid support person. She also meets with Charlotte in her home, and sees that her behaviour is markedly different there, and that she is less agitated. After reviewing all the information collected and consulting the DSM criteria that have been adapted for people with an intellectual disability, the psychologist believes Charlotte's symptoms indicate panic disorder with agoraphobia. Her symptoms are atypical, and are manifesting behaviourally. With the support of her mother and pictorial information sheets, Charlotte is able to understand why she is feeling like she is, and agrees to a course of treatment. Along with developing a behavioural treatment plan, she is referred to a psychiatrist to determine if medication would be beneficial.

3.2 Informed consent and supported decision-making

Gaining knowledge about informed consent and supported decision-making can help to develop the Framework core competencies *1.2 Facilitates supported decision-making and gives priority to the person's expressed wishes, as far as possible* and *6.4 Confirms that the person, their family and support network are aware of the clinical process, and understand their right to be informed, give or withhold informed consent, and of their right to participate in their mental health care.*

Assessing capacity to provide informed consent, and acquiring consent for treatment is vital for all people, including those with an intellectual disability. Supported decision-making should be encouraged, keeping in mind the principle of self-determination as people with an intellectual disability should be involved in the decision-making process to the greatest possible extent. Except in the case of emergency treatment, a person with an intellectual disability cannot be treated without consent. However, some may be assessed as unable to sufficiently understand information surrounding their treatment, or to indicate their choice. In these cases, substitute consent may need to be obtained from a guardian or legally responsible substitute decision maker. [17]

Assessing capacity to consent

To begin with, it should be presumed that the individual with an intellectual disability has capacity to provide informed consent, until they are shown not to (or not to in certain circumstances). Mental health professionals need to assess each person's situation individually in terms of their capacity to carry out the following tasks, as outlined in Figure 3.

Capacity is decision and situation-specific. For example, the individual may be able to consent to a decision about a minor health care issue that is easy to understand (e.g. they will take up regular walking for exercise), but not more complex treatment issues (e.g. taking psychotropic medication). Similarly, they may be able to consent in a calm situation when they have time to process what they are being told.

Consent can be an emergent process, rather than a single event at one point in time. For example, the individual may gain more experience with the assessment and treatment process. Therefore it is important for mental health professionals to re-examine consent throughout their involvement in case the person's capacity to consent changes, or their views about treatment change.

Local procedures should be in place for assessing capacity to consent. *NSW Health guidance around informed consent* provides further information for public mental health professionals.

Supported decision-making

It is important to assist the individual as much as possible so that they can make their own choice. This may involve:

- choosing to discuss treatment options at an appropriate time (e.g. when the person is not tired or exceptionally anxious);
- conveying information using their preferred communication method;
- using simple words (and Easy read written documents);
- giving them more time to process the information;
- conveying concepts with pictures and symbols;
- using concrete examples and diagrams;
- involving support persons to help explain the treatment/procedure; and
- asking the person to paraphrase the information to check their understanding. [25]

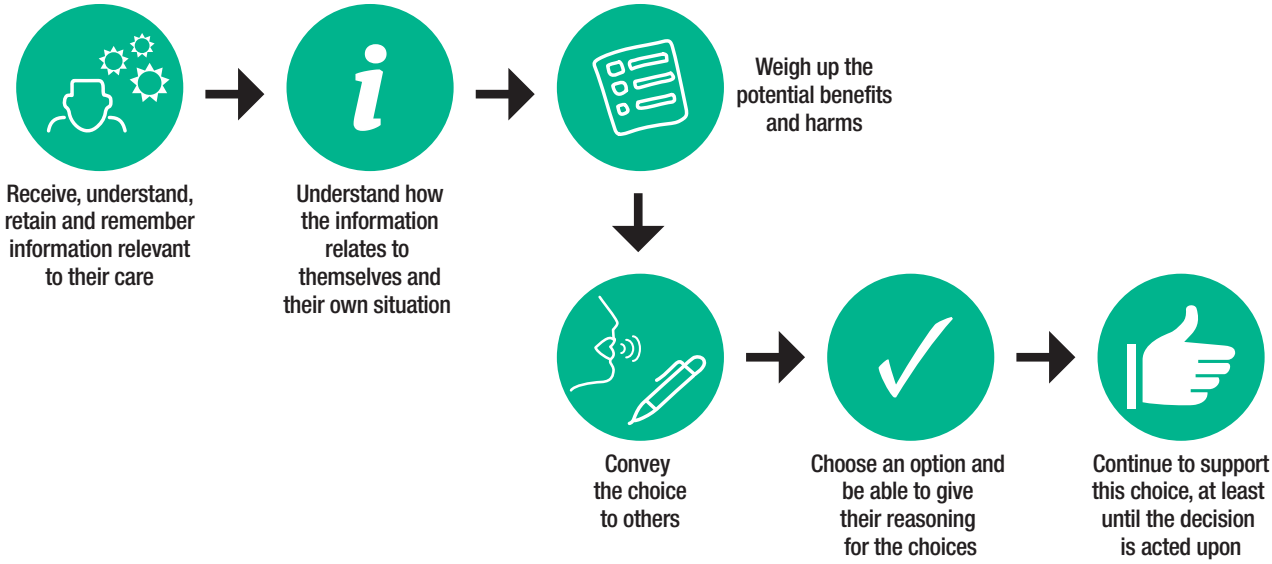
In situations where the person with an intellectual disability cannot make the decision themselves, or cannot convey their choice, they will require a substitute decision-maker to make their mental health care decisions for them.

Substitute decision-makers

If it is decided that a person with an intellectual disability is unable to make decisions about their mental health care, a close relative or unpaid support worker may be able to make decisions on their behalf ('person responsible' or 'statutory health attorney' under relevant guardianship legislation). Once a child reaches 18 years of age, their parents do not have the automatic power to make decisions for them, and state guardianship law applies. However, a parent may still be the most appropriate person responsible.

A paid support worker cannot consent to medical treatment on behalf of an adult lacking the capacity to consent. If there is no appropriate person responsible for decision-making, a guardian needs to be legally appointed.

Figure 3. Steps to making informed decisions



There are procedures in all states and territories for the appointment of a guardian through the guardianship board or tribunal. The guardian is then authorised to make decisions in specific areas of the person with an intellectual disability's life, and for a certain length of time.

For example, decisions about their health care or where they will live. In guardianship, an area of decision making authority is called a function. In some situations, treatment for a mental health disorder may be administered under a specific Mental Health Act.

In NSW, a person can be admitted to hospital involuntarily under the Mental Health Act 2007 (NSW).

Also see Appendix C Part 3 Legal and ethical issues for more information.

4. Treatment

Psychological and pharmacological treatment considerations for people with an intellectual disability are described below, along with when and how to seek specialist assistance.

4.1 Psychological and pharmacological management

Adapting management practices can help to achieve the attributes described in Framework section *9. Mental Health Interventions and Care Planning* and section *2. Recovery Focus.*

While many of the treatment approaches and strategies for mental disorders are similar for the general population and those with an intellectual disability, some modifications are necessary due to the increased complexity of support needs for people with an intellectual disability.

Recovery-oriented mental health practice

The National Standards for Mental Health Services 2010 state that recovery means *"gaining and retaining hope, understanding of one's abilities and disabilities, engagement in an active life, personal autonomy, social identity, meaning and purpose in life, and a positive sense of self"* (p. 42). [26]

In practice this includes:

- viewing the individual with an intellectual disability as an expert in their own life, while the mental health professional can share management knowledge; [27]
- identifying that recovery outcomes are personal to each person, and include quality of life and social inclusion; [26]
- helping people to take as much responsibility for their lives as possible and to continue to build on their strengths; [27]
- focusing on holistic care, and not just reducing the effects of mental illness;
- planning for long-term support and ongoing wellbeing; and
- a combined approach between the individual, mental health professionals, disability and health services, and support networks.

Additional principles underpinning management

There are a number of additional principles that underpin the management of mental disorders in people with an intellectual disability, including:

- Principles such as seeking consent and involving others are also relevant to the treatment stage.
- Treatment planning: designing a comprehensive mental health care plan is especially important; include the person and their support network in the development of the care plan. Take into account support needs, outline the planned intervention and strategies to help the individual participate in treatment, and schedule reviews. The care plan should include strategies for crisis prevention, early intervention, ongoing management strategies and, follow-up. The individual is seen as central to decisions relating to their mental health; they should be provided with choices about their mental health treatment, taking into account their age and capacity. Try to integrate information into a single care plan that governs the services and support they receive. If multiple care plans are unavoidable, check that they are not conflicting.
- Regular monitoring and review: individuals with an intellectual disability and health issues may have difficulty reflecting on how effective their treatment is, and are less likely to report side effects and advocate for themselves. Therefore it is valuable to ask support networks to assist with monitoring. Evaluating and seeking feedback as to how the individual feels about the treatment process is important, checking that they feel included in decisions.

Psychological interventions

Psychological interventions are used as a first-line treatment for many mental disorders. They form the basis of treatment for people with an intellectual disability who present with disorders such as mild depression and mild anxiety. Even when psychotropic medications are indicated as a first-line treatment, psychological interventions should also be considered as a possible adjunct to treatment. While currently limited, evidence suggests that psychological interventions are effective in treating many conditions for these populations. [17]

Mental health professionals can use regular therapy techniques with some modifications, which may include the following in Figure 4.

Figure 4. Modifications to psychological therapy for people with an intellectual disability

Practical adjustments		• Flexible timing, e.g. spending more time building rapport, repeating concepts and material, moving through each step more slowly, having breaks or shorter sessions, and more sessions if required. • Flexible location, e.g. visits to the individual's home may assist engagement.
Involving others		• Family and support people can assist your communication with the individual regarding explaining and implementing psychological interventions. • Psychoeducation can also be provided to the support person regarding the individual's treatment, how they can support therapy strategies (e.g. encouraging self-soothing), and how they can assist with homework tasks. • Support persons can help the individual implement recommended lifestyle changes, and assist with monitoring and seeking follow-up.
Focusing on practical and concrete elements of therapy		• Abstract concepts, which are often discussed in therapy (such as assumptions, empathy and relationships between ideas), can be difficult to grasp for people with an intellectual disability. Reducing the focus on cognitive components, and increasing the focus on behavioural components, is often required. • While working with core thoughts and schemas can be effective for people with borderline/mild intellectual disability (with simplified concepts), for people with moderate to severe intellectual disability, focusing on strategies to manage behaviour and emotions can be more effective. • Simplify psychoeducation provided. • Rather than written notes, clinicians can go through handouts (e.g simplified visual guides) with the individual to ensure they understand all points or steps. • Interventions should be customised to suit the individual's cognitive and language skills e.g. by using diagrams (such as a thermometer to monitor mood), visual cues, pictures, stories and role plays to convey concepts. • Try using homework tasks that are activity based, for example role plays with friends or family. • Applied behavioural analysis can be used before implementing environmental changes that may be maintaining, for example, anxiety or depressed mood.
Handling stigma and discrimination		• People with an intellectual disability often face issues in life that most do not, such as real stigma, discrimination and social exclusion. It is important not to dismiss thoughts regarding issues such as social exclusion as merely a result of low self-esteem or paranoia. Therapy may include helping the individual to live with such situations and to respond appropriately.

A variety of psychological therapies are used for people with an intellectual disability. While there has been limited research into their use with this population, some therapies have more evidence than others for their efficacy. [17]

- *Behavioural therapies* – these have been found to be particularly effective for people with an intellectual disability, and can also be used to deal with irritability or aggression, and to help manage activity scheduling.
- *Cognitive behaviour therapy* – this is used with multiple disorders, for example depression, anxiety, eating disorders, substance use, personality disorders, trauma, anger and aggression. While there is still limited research for its use with people with an intellectual disability, the best evidence for its use is for anger management. Adaptations are usually required, such as longer periods to build rapport, simplified explanations of models and concepts, less complex homework tasks and engaging a support person as a co-therapist.
- *Dialectical behaviour therapy* – while not widely used for people with an intellectual disability, preliminary evidence suggests it may be beneficial for those who do have a personality disorder. [28]
- Other therapies that are used for people with an intellectual disability include supportive therapy, family systems therapy (for both individuals living with their family and in group homes) and psychodynamic therapy. However, research examining their effectiveness with this population is limited.

Pharmacological interventions

It is common for psychotropic medications to be inappropriately prescribed for people with an intellectual disability. This includes their overuse to manage challenging behaviour, [29] excessively prolonged treatment without adequate review, excessive dose, polypharmacy, and ineffective monitoring for side effects. [30]

However, as with the general population, there are situations where pharmacological interventions are indicated as primary treatments. These include, but are not limited to, the management of schizophrenia and related disorders, bipolar disorder, severe anxiety or depressive disorders, milder cases of depression and anxiety that have not responded to psychological treatment alone, and in some situations where complex comorbidities exist. [25]

Generally the principles of prescribing psychotropic medication to people with an intellectual disability are essentially the same as for the general population. While the efficacy of psychotropic drug treatment in this population has not been specifically researched for the majority of psychiatric conditions, it is fair to assume the treatment response will be similar to the general population. Typically psychotropic medications should only be prescribed when a specific mental disorder has been identified. However for individuals with severe to profound levels of intellectual disability where identification is more difficult, medication may be prescribed as a trial, as long as the mental health professional has a good hypothesis as to the likely mental disorder, [17] and is able to follow best practice principles of prescribing and monitoring of response. As with anyone who is prescribed psychotropic medication, careful monitoring of cardiometabolic risk is advisable. Specific resources to assist practice in this area are available on 3DN's Positive Cardiometabolic Health for People with Intellectual Disability website.

Mental health professionals should be aware that there are a number of additional challenges with pharmacological treatment for people with an intellectual disability. These include judgements about when to use psychotropic medication for atypical presentations, how to manage psychopharmacology in the presence of complex health problems, how to minimise polypharmacy and how to communicate effectively to reliably monitor response to treatment and side effects. [31]

There are a number of key strategies for optimal prescribing to consider; see Figure 5 below.

Figure 5. Strategies for optimal prescribing for people with an intellectual disability

Assessment	• Conduct a thorough biopsychosocial assessment before prescribing in order to determine a likely diagnosis, to inform treatment options, and to offer a baseline to measure treatment effectiveness. • Exclude physical and environmental contributions to symptoms. • In situations where psychological or psychosocial interventions are more appropriate, medication should not be used as the first-line intervention, and only considered if the chosen intervention is not effective. • Consider medical comorbidities. For example, if the individual has epilepsy, choose a medication with minimal effects on seizure threshold.
Prescribing	• In general, people with an intellectual disability can experience more side effects from psychotropic medications. Consider prescribing the minimum effective dose and treatment length, which may be less than what would be prescribed for the general population, with potentially smaller dose increments. New medication should be 'trialled' rather than 'commenced'. • Some individuals with an intellectual disability refuse blood tests, so if possible prescribe medication which does not require blood tests to monitor safety. • Provide information to the individual and their support person, including why they are being prescribed the medication, administration, possible adverse reactions, and how to monitor for side effects.
Monitoring	• Monitor medication efficacy and side effects regularly, taking into account that the individual may have difficulty communicating any side effects they are experiencing. • Obtain information from support persons, and pay particular attention to behavioural effects of medication, especially for those with high levels of pre-existing challenging behaviour. • Pay extra attention to potential interactions with existing medication.

Table 6 below summarises some general guidelines when prescribing psychotropic medications to people with an intellectual disability.

Table 6. General guidelines when prescribing psychotropic medications to people with an intellectual disability

Before Prescribing	When Choosing Psychotropic	During Treatment
Determine if prescription is warranted. Is there: • A confirmed diagnosis of mental illness for which psychotropics are indicated AND/OR • Challenging behaviour that is severe and non-responsive to maximal cognitive or behavioural therapy, and is significantly affecting the person's or family/ support persons' life. • Evidence that potential benefits outweigh the risks. Develop a treatment plan detailing: • The person's communication needs. • Targeted behaviour/symptom, frequency and intensity. • How you and others will measure impact of medication on behaviours/symptoms including how effects and side effects will be assessed. • All prior assessments of medical, psychiatric and functional causes of the behaviour/symptom. • Past response to treatment including side effects. • A treatment timeline and plan following the trial. Obtain consent from the individual and/or appointed decision maker.	Consider medical comorbidities and potential medication interactions: • Some syndromes have an increased frequency of cardiometabolic, respiratory disorders or dementia. Avoid medications that will worsen these. • Epilepsy: additional monitoring may be required when prescribing psychotropics that lower the seizure threshold. Consider: • Expressed wishes of the person and primary support persons. • Monitoring requirements of the psychotropic (e.g. blood tests) and whether the person will realistically be able to meet them. • Swallowing or absorption impairments. • Past response to treatment including side effects. • Reviewing co-prescribed psychotropics and taking steps to reduce polypharmacy. • The cardiometabolic liability of the psychotropic.	Commencing Treatment: • Educate the person and their support persons about the psychotropic, indications for treatment and side effects. • Obtain baseline cardiometabolic data. • Commence on a low dose and increase gradually if required. Monitoring Treatment: • Engage the person and their support persons in the monitoring process. • Set regular review times and a timeframe for treatment. • Remember that side effects may be difficult to recognise and report. • Watch for sudden behavioural changes after initiating treatment or increasing dose as this may indicate adverse effects. • Monitor adverse effects on medical comorbidities. Discontinuing Treatment: • Consider discontinuation if ineffective; unacceptable side effects; discontinuation is requested; symptoms have resolved and/or medication is no longer required. • Taper slowly. Avoid simultaneous withdrawal of anticholinergic agents or multiple psychotropics.

Adapted from: Trollor, J.N., Salomon, C., Franklin, C. (2016). Prescribing psychotropic drugs to adults with an intellectual disability, *Australian Prescriber*, *39(4)*, 126-30.

Vignette 6: Management plans

Edward is 12 years of age and has been admitted to the paediatric ward of a regional hospital multiple times in the past year. Admission has been due to aggressive behaviour, believed to be a manifestation of a mental health disorder. Edward's behaviour deteriorated after his family moved interstate, with increased assaultive and self-injuring behaviours. Edward was admitted to the paediatric ward again recently; the family were at the end of their tether and didn't know what else they could do to manage Edward's challenging behaviours.

Edward's history

Edward's early developmental history indicated behavioural problems from 2 1/2 years of age when he became easily frustrated and angry. He developed repetitive behaviours, impaired social skills and physical hyperactivity. He was diagnosed with ADHD at 4 years of age, and intellectual disability and autism at 7 years of age. The family are a cohesive professional family with a good understanding of ASD and ADHD who have been actively involved in Edward's management. There is a strong family history of bipolar disorder. He had been treated in the past with dexamphetamine and more recently with risperidone.

With the recent move, Edward started at the local independent high school but quickly received a suspension for violent behaviour, and was transferred to an ASD support class in the local state school. However after injuring a staff member, he received a 20 day suspension.

During and after recent paediatric admission

When in the hospital paediatric ward, Edward demonstrated poor frustration tolerance and marked anxiety. His previous medication was ceased and his acute anxiety and agitation was treated with olanzapine. A care plan was developed which included strategies for crisis prevention, what steps to take in a crisis, and a long term follow-up plan which included seeing a community clinical psychologist. Psychoeducation was provided to Edward's parents on intellectual disability and co-occurring anxiety, and how this may be affecting his behaviour and cognitions. He was able to return home, and commenced emotional social skills training with a clinical psychologist, who also helped facilitate a slow return to school. His psychologist used very concrete examples during therapy with props to aid understanding, and repeated training exercises often to ensure Edward was confident with these new skills. To facilitate engagement, psychology sessions were held in a room in his house where he felt most calm. His parents have been active in the therapy process, and have been vital in monitoring his progress.

A further crisis admission and failure to respond to a number of ADHD and anxiety medications led to concern that his mood driven behaviour could be a sign of ultra-high risk for early onset bipolar disorder. A review meeting was arranged with Edward's psychiatrist, GP, clinical psychologist, teacher and parents. Subsequent treatment with aripiprazole and lithium improved the clinical course. The family continue to access regular respite and ongoing advice from a CAMHS clinician on behaviour management.

4.2 When and how to seek specialist assistance

Seeking information on specialist IDMH services helps to build the Framework core competency *6.7 Identifies when support is required from specialist intellectual disability mental health professionals, and actively seeks their support*.

Access to specialised IDMH services is currently limited, and varies greatly across Australia. However, where they exist, they provide a valuable service which includes:

- providing advice and a referral pathway for mainstream health/mental health services;
- for complex cases, offering case review and second opinions;
- providing secondary consultations for more comprehensive assessment and care;
- advice on increasing service capacity e.g. educational programs, service model development and inter-service collaboration;
- short-term management until adequate mainstream services are available; and
- utilisation of e-medicine, such as Telemedicine, to increase accessibility of services, such as in rural and remote areas.

When to refer a person with an intellectual disability to a specialist IDMH service:

- when symptoms either do not get better, or progressively become worse despite treatment (e.g. depression symptoms do not get better with the standard age-appropriate intervention);
- the nature of the presentation is particularly complex (e.g. severe intellectual disability, the presence of a complex genetic disorder with medical comorbidity, and psychotic symptoms)
- a more specialised opinion would assist in determining the nature of the problem because it is uncertain;
- the condition requires specialised psychotherapeutic or pharmacological skills;
- there is a deteriorating or unexpected course; or
- there is a continuing high risk to the individual despite treatment (self-harming behaviour or expressed suicidal ideation). [17]

See Resources section 'Seeking specialist assistance' for specialist service details.

Vignette 7: Seeking specialist assistance

Gregory is a 22 year old man with schizophrenia and mild intellectual disability. He lives with his parents, and is visited by a mental health nurse every two weeks. He receives his mental health medication via depot injections regularly. Recently the nurse who visits him has been increasingly concerned about his mental health. He has started drinking alcohol to excess, despite his parents' attempts to stop him. He reports that he is having auditory hallucinations again, and talks regularly about driving himself all over the city, despite not having a licence or access to a car. Even after a review by his psychiatrist, a change in medication, and referral for substance abuse counselling, his mental health has not improved. Due to his complex needs, Gregory's psychiatrist believes he would benefit from a referral to a specialist IDMH service. The service Gregory is referred to conducts a case review, and sees Gregory for a comprehensive assessment session. Afterwards, a case conference is held and a management plan discussed. Advice is provided on medication, and also modified CBT-based techniques. Gregory's psychiatrist also asks about further education on intellectual disability for his department as they do not have anyone in their team who specialises in this area. A specialised educator comes to the department to deliver a workshop on IDMH, discussing the skills and approaches used in the mental health sector, and also information about collaborating with disability sectors. With the new treatment plan, Gregory's nurse starts to see a reduction in his hallucinations and delusions, and his alcohol intake has reduced.

5. Transition

5.1 Transfer of care

Adapting practices to ensure successful transfers of care can achieve the Framework core competencies in part two, section *10. Transfer of care*.

A transfer of care may be required in a number of situations, such as when an individual moves to a new location; or at key transition points in an individual's life (e.g. from child and youth to adult services, from adult to older adult services, and when they become well). In all cases, planning for this transition should begin well in advance, and potential risks associated with the transition be identified.

One key transition stage is discharge from care. Discharge planning should be considered from the time of a comprehensive assessment and be documented in the care plan. Discharge plans should be reviewed regularly, and include:

- a summary of treatment provided and current condition;
- who will be responsible for different aspects of the individual's care if multiple health/disability professionals are involved (and when reviews should take place with them);
- health recommendations; and
- clear steps to take if symptoms re-emerge.

Discussion should take place with the person with an intellectual disability, their family and support networks, and key service providers to plan for the transfer. This is especially important if the individual with an intellectual disability is being discharged from hospital so that the plan is not based on incorrect assumptions (e.g. that their group home is staffed by nursing staff). [25]

Another key transition point for people with an intellectual disability is when they move from child and youth services to adult services. There are not always equivalent adult services, so mental health professionals are encouraged to seek out and research the most appropriate services in their local network, and determine eligibility criteria. Transitions can be stressful, especially if the person with an intellectual disability has seen the same mental health professional for many years. Therefore, transfers of care should not be made during times of psychosocial stress, or if the individual is physically unwell.

To encourage more independence as the person with an intellectual disability approaches young adulthood, it can be beneficial to prepare them for youth and adult mental health services well before they transfer. Depending on capacity, this could include the individual recording the appointment time in their phone/diary, writing down what they would like to ask/discuss before their consultation, and starting to see mental health professionals on their own (even for part of the consultation). This preparation can help the individual to feel more comfortable when they start seeing their new youth or adult mental health team, and encourage continued engagement with mental health services.

Emily Crockford, Sydney Opera House by Night 2014
Acrylic on canvas, 450mm x 450mm, Studio ARTES
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SECTION TWO

Information for service managers

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Information for service managers

This section provides information to assist service managers to develop capacity in IDMH. This can be achieved by including the needs of people with an intellectual disability in the way they develop and run services, and by indicating how they can support their staff to develop core competencies in IDMH.

Adapting service management practices can help mental health professionals to achieve the core competency attributes described in *Section 11. Research, Quality Improvement, and Professional Development of the Framework*.

Developing mental health services that are accessible for people with an intellectual disability can be achieved by making adaptations to existing services; utilising collaborative and multidisciplinary approaches; providing appropriate education and training; and introducing new systems. A review of models of care for people with an intellectual disability found that comprehensive and integrated services including features of both specialist and mainstream services are likely to be most beneficial. [32]

Service managers are responsible for cultivating a workforce proficient in working with people with an intellectual disability. In order to build staff capacity and increase accessibility and inclusivity of the service, a cultural shift within the service toward integration and *active* inclusion of people with an intellectual disability is required (not merely ensuring that people with an intellectual disability are not excluded from services). Steps towards a culture of quality mental health services for people with an intellectual disability may include:

- adopting the Framework and The Guide;
- communicating a high-level commitment to provide equal care for people with an intellectual disability and strong leadership in implementing changes;
- providing mental health professionals and people with an intellectual disability appropriate resources such as brochures in Easy read and Plain English formats; and
- recognising people with an intellectual disability in service documentation.

Service directors and managers should try to include IDMH in local policy and practice frameworks where possible. Clinical governance frameworks and Disability Action Plans should specifically address people with an intellectual disability. These documents are used to inform staff of their responsibility to provide mental health services to people, and guide service delivery. Areas that these documents might address include how to adapt services to meet the needs of people with an intellectual disability, legal aspects of working with this population, clinical pathways within the service, discharge processes and referral pathways, and quality improvement processes (e.g. collecting quality improvement data about people with an intellectual disability who participate in the service).

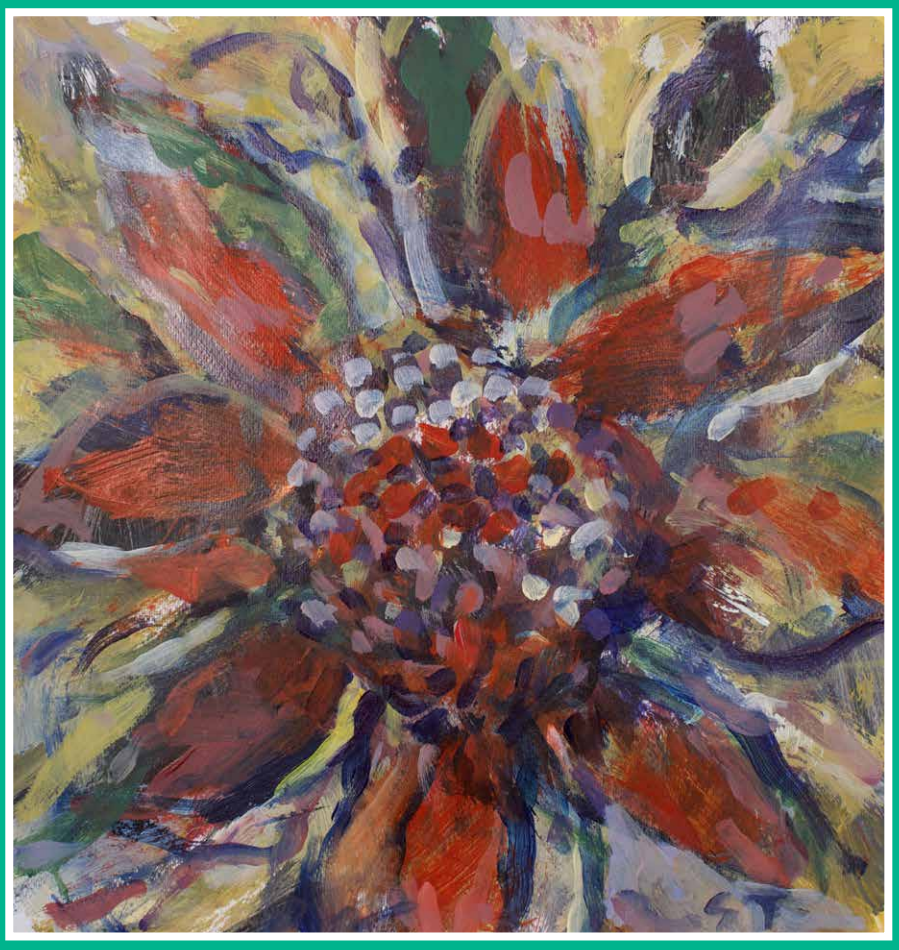
In both community and inpatient mental health settings, service managers can build expertise in intellectual disability within their teams by:

- organising education and training on IDMH;
- providing resources for staff, such as intellectual disability specific assessments and communication tools;
- establishing partnerships with relevant local services such as disability services, social services and mental health professionals who specialise in intellectual disability;
- organising regular, multidisciplinary case reviews;
- developing intellectual disability specific clinical pathways;
- involving people with an intellectual disability in the evaluation of mental health services and decisions about service development (e.g. using surveys, interviews, focus groups, and involvement on committees);
- employing an intellectual disability liaison officer or specialist; and
- measuring the impact of the above strategies and committing to continuous improvement.

Managers can support clinicians to provide health promotion and preventative care to people with an intellectual disability by ensuring appropriate health literacy is available, and promoting early intervention programs. By actively addressing the mental health needs of this high risk population, the health and wellbeing of people with an intellectual disability can be improved over the long term, likely reducing the need for crisis care.

Vignette 8. Implementing IDMH Core Competencies

A community mental health centre in central NSW sees a number of individuals with mild to severe intellectual disability, often complex cases. While one social worker has expertise in intellectual disability, other staff (including psychiatrists, psychologists and mental health nurses) have limited training in the area. The unit manager became aware of the IDMH Core Competencies Framework, and believes that it would be beneficial for staff to enhance their skills in this area as the number of individuals with an intellectual disability referred to their service is rising due to the closure of a nearby disability service. The unit manager introduces the Framework to staff, and encourages them to assess which competencies they already meet using the self-assessment tool. Then, as part of supervision they can determine which competencies would be beneficial to work towards next, and how they would go about this. To start, there is some hesitation as staff feel they will not have time with their heavy workloads. The unit manager acknowledges these concerns, and reassures staff that with some adjustments to the skills they already possess, they can provide improved health services to this population who face significant barriers to care. To help staff get started, a workshop is planned with an educator from a specialist IDMH service. Staff begin to review their competency development as a regular part of supervision, usually taking 5-10 minutes each month. They also access a range of resources, from e-learning to professional development workshops. The social worker with intellectual disability experience becomes the centre's ID 'champion', and provides advice to other staff members. Two of the staff who see the most individuals with intellectual disability, and develop a particular interest in the area, eventually have the review of their competencies included as a formal part of their yearly professional development review.



Glen Turnbull, Waratah 2014
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SECTION THREE

Assessment tools

SECTION THREE

Assessment tools

People with an intellectual disability and co-occurring mental ill health should receive comprehensive, timely and accurate assessment, with assessments that have been validated for use with people with an intellectual disability where possible.

People with an intellectual disability and co-occurring mental ill health should receive comprehensive, timely and accurate assessment, with assessments that have been validated for use with people with an intellectual disability where possible. Regular progress review updates should be provided to the person with an intellectual disability and their family and support persons.

The following section identifies a range of assessment tools that can be used when working with people with an intellectual disability. The assessment tools are divided into six categories: psychopathology, mood, behaviour and emotion, support needs, quality of life and other (which includes social functioning, autism spectrum disorder, dementia and cognitive functioning).

The assessment tools identified in each category are likely to be useful for a broad range of mental health professionals and clinical situations. Each category also contains a link to a list of additional assessment tools. The additional assessment tools may be used less often, require training and/or have more specific domains than the assessments identified in the main text. Brief information is provided on each assessment, including the appropriate age group and its suitability for use in people with different levels of intellectual disability.

Assessment tools

Key: ASD—Autism Spectrum Disorder; ID—Intellectual Disability; PMD—Profound, multiple disabilities; QoL—Quality of life

Psychopathology

Assessment measure	Age group	Level of ID	Description/structure	Administration
Measurement domain: Psychopathology				
Reiss Screen for Maladaptive Behaviour (RSMB; Reiss, 1988)[33] www.idspublishing.com/screen Reiss Scales for Children's Dual Diagnosis www.idspublishing.com/scales/	16 years+ 4-21 years	Mild/ Moderate/ Severe/ Profound	Structure: Adult version: The functioning of an individual is rated for 38 key symptoms of psychopathology. Child version: 60 symptoms of psychopathology are rated by teachers, family or caregivers who know the child well. Purpose: Screens for mental health problems for individuals with an intellectual disability. Aids in identifying individuals who need further psychiatric assessment.	Assessed by: Mental health professional Answered by: Informant

For additional assessments on psychopathology:
http://3dn.unsw.edu.au/idmh-core-competency-framework-toolkit

Mood

Assessment measure	Age group	Level of ID	Description/structure	Administration
Measurement domain: Mood				
Anxiety, Depression and Mood Scale (ADAMS; Esbensen, Rojahn, Aman, & Reudrich, 2003)[34]	10 years and up	Mild/ Moderate/ Severe/ Profound	Structure: 25-item, 5-subscale measure of manic/ hyperactive behaviour, depressed mood, social avoidance, general anxiety and compulsive behaviour. Purpose: Comprehensive screening for anxiety and depression in people with an ID.	Assessed by: Mental health professional Answered by: Informant
Depression in Adults with Intellectual Disability Checklist (Torr & Iacono, 2006)[35] http://www.cddh.monash.org/research/depression	Adult/ Older adult	Mild/ Moderate/ Severe	Structure: One page checklist to be completed by a support person prior to attending a medical or mental health consultation. Purpose: Screening for depression in people with an ID whom are unable to report their own feelings/ symptoms.	Assessed by: Mental health professional Answered by: Informant (specifically designed to be completed by paid carers).
Kessler Psychological Distress Scale (K10; Kessler, Andrews, Colpe, et al., 2002)[36] https://www.tac.vic.gov.au/files-to-move/media/upload/k10_english.pdf	Adult	Borderline/ Mild	Structure: 10-item measure of global distress based on questions about anxiety and depressive symptoms over a 4-week period. Purpose: To assess and monitor distress.	Assessed by: Mental health professional Answered by: Self-report with support person's assistance if required.

For additional assessments on mood: http://3dn.unsw.edu.au/idmh-core-competency-framework-toolkit

Behaviour and emotion

Assessment measure	Age group	Level of ID	Description/structure	Administration
Measurement domain: Behavioural and emotional problems				
Developmental Behaviour Checklist (DBC; Einfeld & Tonge, 2002)[37] Developmental Behaviour Checklist for Adults (DBC-A; Mohr, Tonge, & Einfeld, 2005)[38] http://www.med.monash.edu.au/scs/psychiatry/developmental/clinical-research/dbc/	DBC: 4-18 years DBC-A: Adult/ Older Adult/ ASD	Mild/ Moderate/ Severe	Structure: Questionnaire completed by family, support person or teacher reporting behaviour and emotional problems over a 6-month period. 5 versions are available. A monitoring checklist is also available for specific behaviours. Purpose: Can be used in clinical practice, in assessments and monitoring interventions or research. Different versions have different uses e.g. the DBC-ASA can be used for autism screening.	Assessed by: Mental health professional Answered by: DBC: Family member/teacher Answered by: DBC-A: Family member/paid support person
Measurement domain: Challenging behaviour				
Aberrant Behaviour Checklist (ABC; Aman, Singh, Stewart, & Field, 1985)[39]. ABC-residential and ABC-community versions http://www.slossonnews.com/ABC.html	5-54 years	Moderate/ Severe/ Profound	Structure: 58-item, 5-subscale measure of irritability, agitation and crying; lethargy and social withdrawal; stereotypic behaviour; hyperactivity and non-compliance; and inappropriate speech. 10-15 minutes to complete. Purpose: To assess the effects of treatment or other variables on behaviour; to monitor behaviour over time	Assessed by: Mental health professional Answered by: Informant
Measurement domain: Adaptive and maladaptive behaviour				
Scales of Independent Behavior-Revised (SIB-R; Bruininks, Woodcock, Weatherman, and Hill, 1996) [40] www.riversidepublishing.com/products/sibr/index.html	Three months to 80+ years	Mild/ Moderate/ Severe	Structure: A structured clinical assessment or checklist. A comprehensive, norm-referenced assessment of 14 areas of adaptive behaviour and 8 areas of maladaptive behaviour, in school, home, employment and the community. Purpose: Can be used to determine clinical interventions, develop support plans and assess outcomes.	Assessed by: Mental health professional Answered by: Informant structured interview or checklist

For additional assessments on behaviour and emotion:
http://3dn.unsw.edu.au/idmh-core-competency-framework-toolkit

Support needs

Assessment measure	Age group	Level of ID	Description/structure	Administration
Measurement domain: Mental, physical health and social needs				
Camberwell Assessment of Need for Adults with Developmental and Intellectual Disabilities (CANDID; Xenitidis, Slade, Thornicroft, & Bouras, 2003) [41] www.rcpsych.ac.uk/usefulresources/publications/books/rcpp/1901242994.aspx	Adult	Mild/ Moderate/ Severe	Structure: The CANDID assesses met and unmet needs in 25 areas. It has been developed and tested by a multidisciplinary team at the Institute of Psychiatry, Psychology and Neuroscience in London. Purpose: Designed for mental health staff to undertake a comprehensive assessment of needs for use with adults with an intellectual disability.	Assessed by: Mental health professional Answered by: Perspectives of service user, staff and informal support persons considered

For additional assessments on support needs:
http://3dn.unsw.edu.au/idmh-core-competency-framework-toolkit

Quality of Life

Assessment measure	Age group	Level of ID	Description/structure	Administration
WHO Quality of Life – for persons with disability (WHOQOL-Dis; WHOQOL Group, 1995).[42] Used in conjunction with the WHO Quality of Life-BREF. www.who.int/mental_health/publications/whoqol/en/	Adult	Mild/ Moderate/ Severe	Structure: Different versions of the WHOQOL are available. The WHOQOL-BREF is a 26 item measure and the WHO-DIS is an add-on module that can be used with the WHOQOL-BREF. Measurement domains include physical and psychological health, social relationships, and environment. Purpose: Quality of life assessments can be used to inform clinical decision-making, assist in support planning and development of goals, contribute to evaluation of individual treatment or health services, or be used in research.	Assessed by: Mental health professional Answered by: Self-report or informant

For additional assessments on quality of life:
http://3dn.unsw.edu.au/idmh-core-competency-framework-toolkit

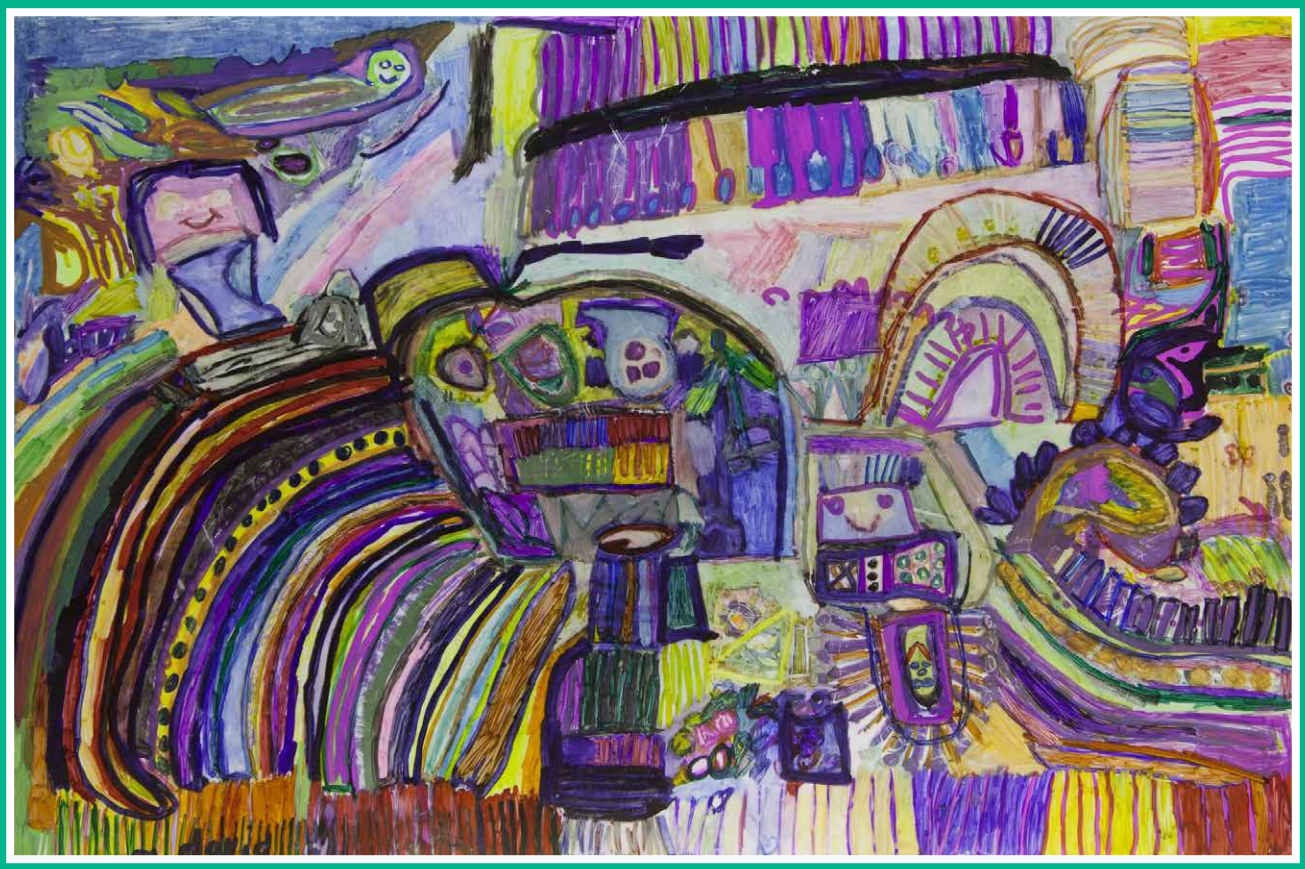
Other assessments

For additional assessments on social functioning, autism spectrum disorder, dementia, and cognitive function:
http://3dn.unsw.edu.au/idmh-core-competency-framework-toolkit

The resource **Assessing Mental Health Concerns in Adults with Intellectual Disabilities – A Guide to Existing Measures** provides an overview of the various measures used to assess mental health concerns in adults with an intellectual disability. It is available for download from http://ddi.wayne.edu/pdf/assessing_mental_health_concerns_in_adults_with_id.pdf

Diagnostic manuals

Diagnosis of psychiatric disorders based on DSM-V or ICD-10 criteria can present challenges when working with people with an intellectual disability. Several diagnostic manuals specific to people with an intellectual disability have therefore been developed. For diagnostic manuals specifically designed for use with people with an intellectual disabilities go to:
http://3dn.unsw.edu.au/idmh-core-competency-framework-toolkit



Rachelle Rodriguez, Rollercoaster 2012
Texta on contact, 400mm x 620mm, Studio ARTES
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SECTION FOUR

Resources

SECTION FOUR

Resources

The following section provides a range of resources which can assist mental health professionals when working with people with an intellectual disability and co-occurring mental ill health.

Vignette 9. Improving practice

After attending a conference where a speaker presented on intellectual disability and psychotropic medication, Olivia, a psychiatry registrar, decided she needed to learn more about treating individuals who have intellectual disability. Recently she had seen a couple of people with mild to moderate levels of intellectual disability, but did not have much experience in the area. She started by searching for some e-learning resources, and completed a number of modules which she found very helpful. Olivia thought about the people with an intellectual disability she had recently seen, and realised that she may have been attributing some of their symptoms to their intellectual disability, rather than their mental health conditions. Following a link from one of the modules, Olivia found some Easy read factsheets to give to people with an intellectual disability on topics such as medication. She arranged with her supervisor to complete a professional development workshop on intellectual disability communication and assessment skills, and circulated a paper on intellectual disability and diagnostic overshadowing for her journal club. Olivia reflected on her personal beliefs about people with an intellectual disability, and realised she had thought that it may be more appropriate for this group to be treated through a disability service. However, she now believes that it is the responsibility of all mental health professionals to treat people with intellectual disability. When Olivia saw her client again who had bipolar disorder and intellectual disability, she employed the skills she had learnt about communication. Discussing his current symptoms, she deduced that they were likely attributable to bipolar disorder, rather than a behavioural aspect of intellectual disability.
This led her to modify his medication which resulted in an improvement.

Training and educational opportunities

Name	Link and Description
Australian education and training	
e-Learning	
Intellectual Disability Mental Health e-Learning	www.idhealtheducation.edu.au This e-Learning website has been developed by the Department of Developmental Disability Neuropsychiatry, UNSW Sydney as a free training resource to improve mental health outcomes for people with an intellectual disability. 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 intellectual disability mental health. For the NSW Health workforce, content from this site is also duplicated for easy access in HETI Online.
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 Royal Australian and New Zealand College of Psychiatrists (RANZCP) E-learning	https://www.ranzcp.org/Publications/E-learning.aspx The RANZCP has developed a range of e-learning resources including three modules on the delivery of mental health services to people with an intellectual disability.
Intellectual Disability – General	
NSW Council for Intellectual Disability Training and Events	http://www.nswcid.org.au/hire-us/training-events.html The NSW Council for Intellectual Disability offers training regarding intellectual disability by people with an intellectual disability, staff and members.
The Queensland Centre for Intellectual and Developmental Disability (QCIDD)	http://www.qcidd.com.au/ QCIDD provides education about the mental and physical health needs of people with an intellectual disability to undergraduate and postgraduate health professionals and the disability workforce. QCIDD has developed many innovative online educational resources, free to the user.
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 health care of people with a developmental disability. CDDVH also offers undergraduate and postgraduate courses and training programs.
Victorian Dual Disability Service (VDDS)	svhm.org.au/home/our-services/departments-and-services/v/victorian-dual-disability-service VDDS is a mental health service for people with an intellectual disability. 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.
Information on Disability Employment Western Australia (ideaswa)	http://www.ideaswa.net/training.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.*
Aboriginal and Torres Strait Islander health	
Australian Indigenous HealthInfoNet	http://www.healthinfonet.ecu.edu.au/ An innovative Internet resource that aims to inform practice and policy in Aboriginal and Torres Strait Islander health by making research and other knowledge readily accessible. It also lists upcoming conferences, workshops and events pertinent to Indigenous Australian health.
HETI Online – Aboriginal Culture – Respecting the Difference	http://www.heti.nsw.gov.au/Courses/Aboriginal-Culture---Respecting-the-Difference/ This online training for NSW Health staff addresses the need for organisations to provide more respectful, responsive and culturally safe services. It is designed to give staff the necessary knowledge and skills to interact positively with Aboriginal people and staff to build positive and meaningful relationships with Aboriginal patients, clients, visitors and staff.
Royal Australian and New Zealand College of Psychiatrists (RANZCP) Aboriginal and Torres Strait Islander mental health resources page	https://www.ranzcp.org/Publications/Indigenous-mental-health/Aboriginal-Torres-Strait-Islander-mental-health.aspx This resources page contains links to a range of useful tools such as e-learning modules

Name	Link and Description
International education and training	
e-learning	
American Association on Intellectual and Developmental Disabilities (AAIDD) e-Learning and Continuing Professional Education	aaidd.org/education/e-learning-and-ceus AAIDD offers online continuing education and training opportunities to intellectual and developmental disability professionals. These courses are available from $10US.
Disability Matters – e-learning to inform and inspire	https://www.disabilitymatters.org.uk E-learning modules on a wide range of topics surrounding disability.
Intellectual disability – general	
British Institute of Learning Disabilities (BILD)	www.bild.org.uk 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 intellectual disabilities and family support persons at the centre of discussion regarding past experiences and future possibilities. BILD also provide a range of factsheets. http://www.bild.org.uk/information/factsheets
Estia Centre – United Kingdom	www.estiacentre.org The Estia Centre, King's College London offers a range of academic and training services to support adults with an intellectual disability and mental health needs through the development of a competent workforce involving a variety of services. Estia offers academic programs and is planning e-learning courses open to anyone who supports people with intellectual disabilities. They also have resources, including a practical guide for supporting complex needs. http://www.slam.nhs.uk/media/199160/complexneeds.pdf
General Medical Council Learning Disabilities – United Kingdom	www.gmc-uk.org/learningdisabilities This site aims to help doctors provide better care for people with intellectual 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 used internationally.

Guides, manuals and toolkits

Name	Link and Description
Intellectual disability	
ACI Intellectual Disability Toolkit	http://www.aci.health.nsw.gov.au/resources/intellectual-disability/toolkit/intellectual-disability-toolkit This is a draft toolkit from the NSW Agency of Clinical Innovation to support the health care of people with an intellectual disability in NSW. Resources include an Easy read appointment letter for the parent or guardian of a person with an intellectual disability, patient journeys and a checklist for including people with disability in programs, procedures and strategies.
Health Care for Adults with Intellectual and Developmental Disabilities Toolkit	http://vkc.mc.vanderbilt.edu/etoolkit/ This e-toolkit has many valuable resources regarding the health and mental health of people with intellectual and developmental disabilities.
Introduction to Intellectual Disability *Intellectual Disability Rights Service*	http://www.idrs.org.au/pdf/IDRS_%20Introduction_intellectual%20disability_17Feb09.pdf An introductory guide on what intellectual disability is, how to recognise it, appropriate language, disability etiquette, communication tips, and disability standards and discrimination.
Working Together 2: Easy steps to improve support for people with learning disabilities in hospital. Guidance for hospitals, families and paid support staff	https://www.improvinghealthandlives.org.uk/publications/1247/Working_together_2:_Easy_steps_to_improve_support_for_people_with_learning_disabilities_in_hospital This guide is an important resource for hospital staff, families and paid support staff when working with people with intellectual disabilities to help them get the care they need while in hospital (from pre-admission planning to discharge). It includes practical suggestions and links to resources.

Name	Link and Description
Working with people with intellectual disabilities factsheet Centre for Developmental Disability Health Victoria (CDDHV)	http://www.cddh.monash.org/assets/documents/working-with-people-with-intellectual-disabilities-in-health-care.pdf This factsheet is a useful summary of information and tips for working with people with an intellectual disability.
Intellectual disability and mental health	
A Manual of Cognitive Behaviour Therapy for People with Learning Disabilities and Common Mental Disorders: Therapist Version. A. Hassiotis, M. Serfaty, K. Azam, S. Martin, A. Strydom, & K. King (2012)	https://www.ucl.ac.uk/psychiatry/cbt/downloads This UK manual describes the process of treating depression and/or anxiety disorders for people with mild to moderate intellectual disabilities using CBT. It is designed for therapists who have CBT training, but have little to no experience with clients who have intellectual disability.
Mental Health and Wellbeing Practice Guide for Psychologists who Support People with Disability and Appraisal form	https://www.adhc.nsw.gov.au/sp/delivering_disability_services/core_standards/psychology This discipline specific core standard for psychologists provides evidence-based information regarding people with an intellectual disability and co-occurring mental ill health. It is also used to promote good communication channels and collaboration between services. It is designed to be complementary to the common core standards programs.
Practice Guidelines for the Assessment and Diagnosis of Mental Health Problems in Adults with Intellectual Disability. Shoumitro Deb, Tim Matthews, Geraldine Holt & Nick Bouras	https://www.iassidd.org/uploads/legacy/images/documents/other/deb_et_al_european_id_practice_guidelines_29_10_09.pdf A series of Practice Guidelines for those working with people with an intellectual disability to encourage and promote evidence-based practice.
Behaviour support	
ADHC Behaviour support policy and practice manual	http://www.adhc.nsw.gov.au/sp/delivering_disability_services/behaviour_support_services/behaviour_support_policy_and_practice_manual ADHC has published a Behaviour Support Policy and Practice Manual outlining the minimum requirements and guidelines for ADHC services in providing a behaviour support service to adults, children or young people with an intellectual disability.
Behaviour Support Plan Toolkit, Department of Human Services, Victoria	http://www.dhs.vic.gov.au/__data/assets/pdf_file/0011/845345/Toolkit-section-1-Why-develop-good-quality-plans-0913.pdf This is a brief toolkit with information and guidance on how to develop a behaviour support plan. Quality behaviour support plans are associated with reductions in the use of restrictive interventions.
Problem Behaviours in Adults with an intellectual disability: An International Guide for Using Medication	http://www.wpanet.org/uploads/Sections/Psychiatry_Intellectual/WPA-SPID-International-Guide.pdf This guide from The Section of Psychiatry of Intellectual Disability (SPID): World Psychiatric Association (WPA) outlines advice when considering prescribing medications to manage problem behaviours among adults with an intellectual disability. They were adapted from UK guidelines that followed National Institute for Health and Clinical Excellence, UK (NICE) guidelines.
Complex needs	
Working with People who have a Learning Disability and Complex Needs: The Essentials	http://www.nes.scot.nhs.uk/media/579631/complex_needs_final.pdf This guide aims to offer professionals supporting individuals with an intellectual disability and complex needs opportunities to develop their knowledge, skills and values in ways that maximise the involvement of consumers, and family and support persons to increase health and wellbeing.
Forensic populations	
People who have an Intellectual Disability and the Criminal Justice System Villamanta Disability Rights Legal Service Inc.	http://www.villamanta.org.au/documents/People%20with%20ID%20in%20Criminal%20Justice%20System.pdf This is a guide and educational tool designed for individuals working in the criminal justice system, but is a useful tool for any professional who would like further information on the criminal justice system for individuals with an intellectual disability. It includes information on police interviews, advocacy, court services and criminal sentencing.

Name	Link and Description
Capacity to consent and supported decision-making	
General Guidelines for Medical Practitioners on Providing Information to Patients	https://www.nhmrc.gov.au/_files_nhmrc/publications/attachments/e57_guidelines_gps_information_to_patients_150722.pdf These guidelines are an NHMRC resource that provides guidance on informed consent, supported decision-making, and substitute decision-making.
NSW Government Capacity Assessment Tools	http://www.justice.nsw.gov.au/diversityservices/Pages/divserv/ds_capacity_tool/divserv_assess_principles.aspx This website outlines capacity assessment principles, when capacity should be assessed and who might assess capacity. There is also a useful toolkit to determine whether an individual has the capacity to make their own decisions. See page 103 for a capacity checklist http://www.justice.nsw.gov.au/diversityservices/Documents/capacity_toolkit0609.pdf
Mental Health Rights Manual	http://mhrm.mhcc.org.au/chapter-5/5e.aspx The Mental Health Coordinating Council has published the Mental Health Rights Manual, which sets out who can make decisions- either the person responsible or the public guardian, depending on the kind of treatment proposed (this manual is specific to NSW).
Ethical Guidelines for Doctors on Disclosing Medical Records to Third Parties	https://ama.com.au/position-statement/guidelines-doctors-disclosing-medical-records-third-parties-2010 The Australian Medical Association has published privacy guidelines for doctors which may be of interest to other professions as well.
Clinical pathways	
Integrated Care Pathways: A Guide to Good Practice. *National Leadership and Innovation Agency for Healthcare NHS Wales*	http://www.wales.nhs.uk/sitesplus/documents/829/integratedcarepathways.pdf This guide assists clinical teams in Wales to implement the Integrated Care Pathways program, and can be used to find out more information about care pathways and how they are developed.

Additional website resources

Name	Link and Description
Children's Hospital Westmead (CHW) School-Link	http://www.schoollink.chw.edu.au/ This website provides information on supporting the mental health of children and adolescents with an intellectual disability.
Complex Needs Capable: A practice resource for drug and alcohol services	http://www.complexneedscapable.org.au/intellectual-disability.html Information for professionals working with people with complex needs in drug and alcohol services.
Consent and People With Intellectual Disabilities: The Basics	http://www.intellectualdisability.info/how-to../consent-and-people-with-intellectual-disabilities-the-basics This website gives a good outline of the ethical concepts involved in consent for people with an intellectual disability.
Jenny's Diary, a resource to support conversations about dementia with people who have an intellectual disability, University of the West of Scotland; Karen Watchman, Irene Tuffrey-Wijne, Sam Quinn	www.uws.ac.uk/jennysdiary *Jenny's Diary* is a free booklet and a set of postcards aimed at supporting conversations about dementia with people who have an intellectual disability. Both PDF and ebook versions are available for download.
"Listening to those rarely heard" Scope Victoria video	http://vimeo.com/21176882 Scope Victoria has created a video on supporting decision-making by people with severe-profound intellectual disability: "Listening to those rarely heard". This video outlines important concepts that underlie empowering people with an intellectual disability to make decisions, and examines these specifically with people with severe to profound intellectual disability.

Name	Link and Description
The Mental Health in Multicultural Australia project	http://www.mhima.org.au/ This project is funded by the Australian Government Department of Health, to provide a national focus for advice and support on mental health and suicide prevention for people from CALD backgrounds. The website provides a range of resources and information including a framework for providing multicultural mental health services.
National Human Rights Action Plan	http://www.humanrightsactionplan.org.au/nhrap/ As part of Australia's Human Rights Framework, the Australian Government is developing a new National Human Rights Action Plan. This presents an opportunity to systematically consider Australia's strengths and address our shortcomings in human rights laws and practice.
PMLD Network resources	http://www.pmldnetwork.org/resources/index.htm The PMLD Network provides a range of resources about issues affecting people with profound and multiple intellectual disabilities.
Positive Cardiometabolic Health for People with Intellectual Disability website	https://3dn.unsw.edu.au/positive-cardiometabolic-health-ID A major contributor to health inequality is the high rate of cardiometabolic disease experienced by people with an intellectual disability. The *Positive Cardiometabolic Health for People with an Intellectual Disability: an Early Intervention Framework* guides medical professionals through cardiometabolic risk screening for adults and adolescents, provides tailored intervention strategies, identifies specific syndromes with altered cardiometabolic risk profiles, and links to accessible resources for clinicians, people with an intellectual disability and carers. Postcards with information about cardiometabolic risk are also available for people with an intellectual disability and their support network to print off and take to their doctor.
Syndrome Sheets, The Society for the Study of Behavioural Phenotypes (SSBP)	http://www.ssbp.org.uk/syndromes.html. Certain genetic disorders that cause intellectual disability are associated with particular patterns of behaviour called behavioural phenotypes. Becoming familiar with behavioural phenotypes can help interpret symptoms and formulate management plans. The SSBP have created a portfolio of Syndrome Sheets, written by members with specific expertise in the treatment of a variety of syndromes.
The UK Health and Learning Disability Network	http://www.learningdisabilities.org.uk/help-information/uk-health-learning-disability-network The UK Health and Learning Disability Network (UKHLD) is a national community of people interested in health and people with intellectual disabilities. They aim to assist health practitioners in both mainstream and specialist services. The network produces a weekly email newsletter, Health Stones.
Valuing People Now, United Kingdom	http://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 individuals with an intellectual 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.

Books

Name	Link and Description
Intellectual disability and mental health	
Clinical Psychology and People with Intellectual Disabilities, 2nd Edition Edited by Eric Emerson, Chris Hatton, Kate Dickson, Rupa Gone, Jo Bromley & Amanda Caine. John Wiley & Sons (2012)	http://au.wiley.com/WileyCDA/WileyTitle/productCd-0470029714.html This book is a comprehensive resource presenting current evidence-based practices and relevant clinical skills for working with people with an intellectual disability. The book is beneficial for mental health professionals and allied health staff including psychologists, psychiatrists, nurses and social workers.
Cognitive-behaviour therapy for people with learning disabilities Edited by Biza Stenfert Kroese, Dave Dagnan, and Konstantinos Loumidis. Psychology Press (1997)	https://www.amazon.com/Cognitive-Behaviour-Therapy-People-Learning-Disabilities/dp/0415127513 Cognitive-behaviour therapy for people with learning disabilities explores theoretical and practical issues surrounding the application of cognitive therapy to people with an intellectual disability. It provides a wealth of practical examples for training and is a valuable resource for clinical psychologists, psychiatrists and all researchers and practitioners who see people with an intellectual disability.
Management Guidelines: Developmental Disability, Version 3, 2012 Therapeutic Guidelines Limited (2012)	https://tgldcdp.tg.org.au/fulltext/quicklinks/management_guideline.pdf These 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 for people who are not professional health care workers.
Management of Mental Disorders, Version 5, 2013 Gavin Andrews, Kimberlie Dean, Margo Genderson, Caroline Hunt, Philip Mitchell, Perminder Sachdev, and Julian Trollor (2013)	https://crufad.org/index.php/component/content/article/64-mm5 This book provides practical guidance on recognising and treating mental disorders. *Chapter 7: Neurodevelopmental Disorders* contains information on intellectual disability. The book also includes resource materials such as outcome measures, worksheets and information pamphlets for individuals with mental disorders and their families.
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 ill health. It provides useful information on how this population's complex developmental, emotional, and behavioural needs might best be addressed. It also includes a model for how interdisciplinary and multi-service collaboration and coordination might be facilitated, and information on the integration of biological, developmental, family, educational, social and cultural factors.
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 intellectual disability. It focuses on the ways that theories and policies have been applied to clinical practice.
Psychiatric and Behavioural Disorders in Intellectual and Developmental Disabilities, Third Edition Edited by Colin Hemmings & Nick Bouras. Cambridge University Press (2007)	http://www.cambridge.org/ar/academic/subjects/medicine/mental-health-psychiatry-and-clinical-psychology/psychiatric-and-behavioral-disorders-intellectual-and-developmental-disabilities-3rd-edition?format=PB 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)	http://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 intellectual disability. A resource for those in specialist training, or those seeking a better understanding of intellectual disabilities.

Name	Link and Description
ICD-10 Guide for Mental Retardation	http://www.who.int/mental_health/media/en/69.pdf This is an adapted version of the ICD-10 International Statistical Classification of Diseases and Related Health Problems for individuals with an intellectual disability.
Intellectual disability and dementia	
Intellectual Disability and Dementia: Research into Practice Edited by Karen Watchman. Jessica Kingsley Publishers (2014)	http://www.jkp.com/uk/intellectual-disability-and-dementia.html This book provides up to date information on best practice for people with an intellectual disability and dementia and clearly describes the relevance and implications of available research for support and services.
Behaviour	
Challenging Behaviour, 3rd Edition Eric Emerson and Stewart Einfeld, Cambridge University Press (2011)	http://www.cambridge.org/au/academic/subjects/medicine/mental-health-psychiatry-and-clinical-psychology/challenging-behaviour-3rd-edition This book provides a concise, accessible and contemporary summary of current knowledge about challenging behaviour, drawn from psychology, psychiatry, medicine and public health.
Positive Behaviour Support for People with intellectual disability: Evidence-based practice promoting quality of life Edited by Keith McVilly. ASID (2003)	http://www.asid.asn.au/product/view/4 This book presents a holistic, biopsychosocial approach to behaviour support designed to promote quality of life for people with an intellectual disability. 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.

Reports and discussion papers

Name	Link and Description
Cross sector service coordination for people with high and complex needs: Harnessing existing evidence and knowledge	http://sydney.edu.au/health-sciences/cdrp/discussion-paper-complexneeds-july2014.pdf A discussion paper from the Centre for Disability Research and Policy, University of Sydney and the Young People In Nursing Homes National Alliance.
Current models of health service delivery for people with intellectual disability: Literature review Gianfranco Giuntoli, B.J. Newton and Karen R. Fisher, Social Policy Research Centre, UNSW Australia.	http://www.sprc.unsw.edu.au/media/SPRCFile/SPRC_Report_Current_Models_of_Health_Service_Delivery_for_People_with_Intellectual_Disability.pdf This report details a literature review on current models of health service delivery for people with an intellectual disability. The review identified nine models of health service delivery for people with an intellectual disability, two from Australia and seven from the UK.
Models of Service Provision to Adults with an Intellectual Disability with Co-existing Mental Illness, The University of Queensland	https://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 government and non-government services.
A predictable and preventable path: Aboriginal people with mental and cognitive disabilities in the criminal justice system Eileen Baldry, Ruth McCausland, Leanne Dowse and Elizabeth McEntyre	https://www.mhdcd.unsw.edu.au/sites/www.mhdcd.unsw.edu.au/files/u18/pdf/a_predictable_and_preventable_path_2nov15.pdf This report provides a critical analysis of systems interactions and responses to the complex needs of Indigenous people with disability in the criminal justice system.
Psychological therapies and people who have intellectual disabilities British Psychological Society	http://www.bps.org.uk/system/files/Public%20files/Policy/psychological_therapies_and_people_who_have_id_pdf_for_review.pdf This report on psychological therapies and people with intellectual disability informs professionals, managers, carers and people with intellectual disability as to what psychological therapies may best help with, and what the likely outcomes are.
Talking about sex and relationships: the view of young people with learning disabilities *The final report of the sexuality project by CHANGE, 2007-2010*	http://www.changepeople.org/free-resources/ This report discusses the Sex and Relationships project undertaken by CHANGE, UK, a learning organisation led by people with disabilities. Young people with an intellectual disability, along with parents, were interviewed about sex and relationships, including same sex relationships.

Selected journal articles

Name	Reference
Intellectual disability mental health	Trollor, J. (2014). Making mental health services accessible to people with an intellectual disability. *Australian and New Zealand Journal of Psychiatry, 48*(5), 395-398.
Psychotropic medication	Deb, S., Unwin, G., & Deb, T. (2015). Characteristics and the trajectory of psychotropic medication use in general and antipsychotics in particular among adults with an intellectual disability who exhibit aggressive behaviour. *Journal of Intellectual Disability Research, 59*(1), 11-25.
	Trollor, J.N., Salomon, C., Franklin, C. (2016). Prescribing psychotropic drugs to adults with an intellectual disability*, Australian Prescriber,* 39(4), 126-130.
Behavioural phenotypes	O'Brien, G. (2006). Behavioural phenotypes: causes and clinical implications. *Advances in Psychiatric Treatment, 12*(5), 338-348.
Forensic populations	Baldry, E., Clarence, M., Dowse, L., & Trollor, J. (2013). Reducing vulnerability to harm in adults with cognitive disabilities in the Australian criminal justice system. *Journal of Policy and Practice in Intellectual Disabilities, 10*(3), 222-229.
	Dias, S., Ware, R. S., Kinner, S. A., & Lennox, N. G. (2013). Co-occurring mental disorder and intellectual disability in a large sample of Australian prisoners. *Australian and New Zealand Journal of Psychiatry, 47*(10), 938-944.
Clinical pathways	Wood, S., Gangadharan, S., Tyrer, F., Gumber, R., Devapriam, J., Hiremath, A., & Bhaumik, S. (2014). Successes and Challenges in the Implementation of Care Pathways in an Intellectual Disability Service: Health Professionals' Experiences. *Journal of Policy and Practice in Intellectual Disabilities, 11*(1), 1-7.
Health care culture change	Scott, T., Mannion, R., Davies, H. T., & Marshall, M. N. (2003). Implementing culture change in health care: theory and practice. *International Journal for Quality in Health Care*, 15(2), 111-118.

Relevant mental health policy documents and competency frameworks

Name	Link
International	
United Nations Universal Declaration of Human Rights	http://www.un.org/en/documents/udhr/index.shtml
United Nations Convention on the Rights of Persons with Disabilities	https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/convention-on-the-rights-of-persons-with-disabilities-2.html
United Nations Convention on the Rights of the Child	http://www.unicef.org/crc/
Madrid International Plan of Action on Ageing and the Political Declaration	http://www.un.org/en/events/pastevents/pdfs/Madrid_plan.pdf
National	
Legislations and acts	
Australian Human Rights Commission Act 1986	http://www.comlaw.gov.au/Search/Australian%20Human%20Rights%20Commission%20Act%201986
Disability Discrimination Act 1992	http://www.comlaw.gov.au/Series/C2004A04426
A quick guide to Australian discrimination laws	https://www.humanrights.gov.au/employers/good-practice-good-business-factsheets/quick-guide-australian-discrimination-laws
Racial Discrimination Act 1975	http://www.comlaw.gov.au/Series/C2004A00274
Health Practitioner Regulation National Law Act 2009	http://www.ahpra.gov.au/Legislation-and-Publications/Legislation.aspx

Name	Link
Health	
Australia's Health Workforce – Productivity Commission Research Report 2005	http://www.pc.gov.au/inquiries/completed/health-workforce/report/healthworkforce.pdf
National Health Workforce Innovation and Reform Strategic Framework for Action 2011–2015	http://www.qrtn.com.au/images/pdf/Resources/hwa-wir-strategic-framework-for-action-201110.pdf
A Healthier Future for All Australians	http://www.health.gov.au/internet/nhhrc/publishing.nsf/content/1AFDEAF1FB76A1D8CA257600000B5BE2/$File/Final_Report_of_the%20nhhrc_June_2009.pdf
Mental Health	
Accessible Mental Health Services for People with an Intellectual Disability: A Guide for Providers	https://3dn.unsw.edu.au/the-guide
Fourth National Mental Health Plan and National Mental Health Strategy	http://www.health.gov.au/internet/main/publishing.nsf/content/mental-pubs-f-plan09
National Mental Health Workforce Strategy	http://webarchive.nla.gov.au/gov/20141216070240/http://www.health.gov.au/internet/mhsc/publishing.nsf/Content/pub-mhwac-strat
National Practice Standards for Mental Health Workforce	http://www.health.gov.au/internet/main/publishing.nsf/Content/mental-pubs-n-wkstd13
National Standards for Mental Health Services	www.health.gov.au/internet/main/publishing.nsf/content/mental-pubs-n-servst10
Mental Health Statement of Human Rights and responsibilities (2012)	http://www.health.gov.au/internet/publications/publishing.nsf/Content/pub-sqps-rights-toc
National Mental Health Policy	http://www.health.gov.au/internet/main/publishing.nsf/Content/mental-pubs-n-pol08
The Roadmap for National Mental Health Reform 2012-2022	http://www.coag.gov.au/sites/default/files/communique/The%20Roadmap%20for%20National%20Mental%20Health%20Reform%202012-2022.pdf
A National Framework for Recovery-oriented Mental Health Services 2013	http://www.health.gov.au/internet/main/publishing.nsf/Content/mental-pubs-n-recovfra
Disability	
National Disability Strategy 2010-2020	http://www.fahcsia.gov.au/disability-and-carers/news/2011/national-disability-strategy-2010-2020
State	
Legislation	
Mental Health Act 2007 No 8	http://www.legislation.nsw.gov.au/maintop/view/inforce/act+8+2007+cd+0+N Mental Health Act (2007) Guidebook: http://www.health.nsw.gov.au/mhdao/publications/Publications/pub-act-2007-guide.pdf
Guardianship Act	http://www.legislation.nsw.gov.au/maintop/view/inforce/act+257+1987+cd+0+N
The NSW Anti-Discrimination Act 1977	http://www.legislation.nsw.gov.au/viewtop/inforce/act+48+1977+FIRST+0+N/
Disability Inclusion Act 2014	http://www.legislation.nsw.gov.au/maintop/view/inforce/act+41+2014+cd+0+N
Policies and plans	
NSW State Plan 2021	http://www.ipc.nsw.gov.au/sites/default/files/file_manager/NSW2021_WEBVERSION.pdf
NSW Service Plan for Specialist Mental Health Services for Older People	http://www0.health.nsw.gov.au/policies/gl/2006/pdf/GL2006_013.pdf
NSW Health: Your Health Rights and Responsibilities	http://www.health.nsw.gov.au/policies/pd/2011/PD2011_022.html
NSW Carers Strategy 2014-2019	http://www.adhc.nsw.gov.au/__data/assets/file/0017/300077/NSW_Carers_Strategy_2014-19.pdf

Name	Link
LHD Disability Action Plans	Illawarra Shoalhaven http://www.islhd.health.nsw.gov.au/ISLHDDisabilityActionPlan2014_2.pdf Nepean Blue Mountains http://www.nbmlhd.health.nsw.gov.au/ArticleDocuments/273/NBMLHD%20Disability%20Action%20Plan%20-%20FINAL%20November%202014.pdf.aspx Northern Sydney http://www.nslhd.health.nsw.gov.au/AboutUs/publications/Documents/NSLHD%20Disability%20Action%20Plan%202011%202016%20updated%20-%2021%20November%202013.pdf South Eastern Sydney http://www.seslhd.health.nsw.gov.au/HealthPlans/documents/SESLHD_Disability_%20Action_Plan_2012-15.pdf Sydney http://www.slhd.nsw.gov.au/pdfs/SLHD_DisabilityActionPlan2014_2019.pdf
NSW Interagency Action Plan for Better Mental Health	http://www.nada.org.au/media/8053/interagency_mh_plan.pdf
NSW: A New Direction for Mental Health	http://www.nada.org.au/media/8047/mental_health_new_direction.pdf
NSW Community Mental Health Strategy 2007-2012	http://www.health.nsw.gov.au/mentalhealth/programs/mh/Pages/mental-health-strategy.aspx
Living Well: A Strategic Plan for Mental Health in NSW	https://nswmentalhealthcommission.com.au/our-work/strategic-plan/downloads
Charter	
Charter for Mental Health Care in NSW (2000)	http://www.health.nsw.gov.au/mentalhealth/Pages/charter.aspx
Competency frameworks	
NSW Child and Adolescent Mental Health Services	http://www.health.nsw.gov.au/mentalhealth/programs/mh/Pages/camhs-compfrmwk.aspx
Core Competencies for SMHSOP Community Clinicians	http://www.health.nsw.gov.au/mentalhealth/programs/mh/Documents/core-comp-measurcrit-beginclinic.pdf
Disability/intellectual disability specific documents	
Service Framework to Improve the Health Care of People with Intellectual Disability	http://www.health.nsw.gov.au/disability/Publications/health-care-of-people-with-ID.pdf
Memorandum of Understanding between Ageing, Disability and Home Care and NSW Health in the provision of services to people with an intellectual disability and mental illness	https://www.adhc.nsw.gov.au/__data/assets/file/0010/237277/MOU_ADHC_and_NSW_Health_2010.pdf
Responding to Needs of People with Disability during Hospitalisation	http://www0.health.nsw.gov.au/policies/pd/2017/PD2017_001.html
Disability Services Supporting Decision-Making: A guide to supporting people with a disability to make their own decisions	http://www.dhs.vic.gov.au/about-the-department/documents-and-resources/policies,-guidelines-and-legislation/supporting-decision-making-guide
Personal relationships, sexuality and sexual health policy and guidelines	http://www.dhs.vic.gov.au/__data/assets/pdf_file/0008/604583/dsd_personal_relationships_sexual_health_policy_250506.pdf An example of a policy document on sexual health and disability from the Victorian government, which also references LGBTIQ individuals.

Seeking specialist assistance

Name	Link and Description
3DN Clinic for the Assessment of Neuropsychiatric Disorders in Intellectual Disability (CANDID)	https://3dn.unsw.edu.au/clinics CANDID is a tertiary outpatient service which aims to support specialists working with people with an intellectual disability by providing second opinions on complex cases. It is also an important training resource for medical students, psychiatry trainees and IDMH Fellows. It is located in the EUROA Centre at the Prince of Wales Hospital, Randwick. Referrals are accepted from specialists currently managing patients 18 years and older who will be offering continuing care (those aged 16-17 years will be considered after discussion).
NSW Ministry of Health funded Specialist multidisciplinary intellectual disability health team pilots	– Northern Intellectual Disability Health http://cds.org.au/?s=northern+sydney+intellectual+disability+health&submit=Go Northern Intellectual Disability Health is a multidisciplinary health service for school aged children, adolescents and adults with an intellectual disability and complex health needs. This service is operated by the Centre for Disability Studies, and provides medical and health consultations, advice and referrals. It works in conjunction with the patient's GP and/or paediatrician, other health services and disability service providers to deliver coordinated health care. People with an intellectual disability who live in the Northern Sydney Local Health District are eligible to be seen at the clinic. – Kogarah Diagnostic and Assessment Services/Metro-regional Intellectual Disability Network (MRID.net) http://www.datadiction.com.au/bin/dd.dll/Lincs?xpsRec&MBR=KOG&SID=63116 MRID.net is a specialist multidisciplinary health service led by the Kogarah Diagnostic and Assessment Service (DAS) at St George Hospital. This network aims to develop a partnership model of service delivery using the existing services in South East Sydney LHD to establish an inter-regional specialised health service for individuals with an intellectual disability and complex health needs in both South East Sydney and metropolitan and regional NSW, with a focus on Illawarra Shoalhaven LHD. The target group is children, adolescents and adults with developmental delay/disabilities and associated health and mental health conditions. Specialist clinic services include paediatric and adult psychiatry. They have also developed http://schoolkit.org.au/. This schoolkit provides the key tools to help you set up and maintain school-based clinics to support children and adolescents with complex needs. – Specialist Disability Health Team (SDHT) http://www.schn.health.nsw.gov.au/parents-and-carers/our-services/developmental-delay-and-intellectual-disability/chw The SDHT is a service of the Sydney Children's Hospital Network, and is located in Fairfield within the boundaries of the Sydney South West LHD. The SDHT's directive is broad, and includes providing specialist health care delivery, developing clinical pathways, service networks and resources, undertaking research and building capacity within mainstream health care services. The team provides comprehensive health assessments to school aged children with an intellectual disability up to the age of 18 years. In addition to twice-weekly multidisciplinary paediatric clinics and monthly school clinics where comprehensive health assessments are completed, a specialist mental health clinic is held monthly.
NSW Developmental Disability Health Unit	http://cds.org.au/clinics-services/royal-rehab-clinic-ddhu/ The NSW Developmental Disability Health Unit provides a consultation service for adolescents and adults with developmental disabilities, their family and support persons. It is a state-wide health clinic based at the Royal Rehab Hospital in Ryde. Services include the treatment of mental health and emotional disorders.
The Royal Australian & New Zealand College of Psychiatrists Find a Psychiatrist	https://www.ranzcp.org/Mental-health-advice/find-a-psychiatrist.aspx Individuals can search for RANZCP psychiatrists by primary problem area, population treated, location, name, treatments and services, and language spoken.
The Royal Australian and New Zealand College of Psychiatrists-Section of Psychiatry of Intellectual and Developmental Disabilities (SPIDD)	https://www.ranzcp.org/Membership/Faculties-sections/Intellectual-Developmental-Disabilities.aspx The SPIDD, which has a NSW arm, can provide clinical support and peer review. See the SPIDD newsletter for contact details.

Name	Link and Description
Intellectual Disability Mental Health Service (IDMHS) at Concord Repatriation General Hospital	The Intellectual Disability Mental Health Service (IDMHS) is a specialised health care service for people with intellectual or developmental disabilities who are in need of mental health interventions. The service aims to support existing community mental health patients with an intellectual disability by offering review and advice to current teams and assistance with liaison between the mental health and disability sectors. The service also assists in providing comprehensive assessments and implementing hospital management plans for complex needs patients with an intellectual disability. The service is run through a weekly adult outpatient clinic located within the Department of Aged, Chronic Care & Rehabilitation at the Concord Repatriation General Hospital. In addition, the service also provides specialist consultations to local community health centres and adult hospital inpatient units located within the Sydney Local Health District (SLHD). There is also a limited provision for patients outside the area to access the clinic. The service is for patients aged 18 years and over (or 17 years and over for people transitioning from a paediatric disability service). Outpatient referrals can be made via the Access Care Team on 1300 722 276. For more information call (02) 9767 7278 or (02) 9767 5730.
Australian Psychological Society Find a Psychologist	https://www.psychology.org.au/FindaPsychologist/ Individuals can search for APS psychologists by primary problem area, location and name.
ACT Mental Health Service for People with Intellectual Disability (MHS-ID)	The ACT Mental Health Service for People with Intellectual Disability (MHS-ID) is a specialist team within the ACT Mental Health, Justice Health and Alcohol and Drug Service (MHJHADS). It is now located at the Gungahlin Community Health Centre and provides comprehensive clinical assessment and psychiatric treatment to individuals with a known or suspected intellectual disability and a known or suspected mental illness or mental disorder. Referrals are open to individuals with Autism Spectrum Disorder with or without intellectual disability. MHS-ID liaises with all teams within MHJHADS, including child and adolescent services and inpatient units, GPs, specialists, allied health professionals, and non-government disability services in the ACT. MHS-ID provides ongoing treatment until stabilisation of the presenting condition and undertakes neuropsychological assessments as required. It consists of a 0.2 FTE staff psychiatrist, a 0.1 FTE VMO psychiatrist, psychologists and registered nurses, plus administrative support staff. To contact the service phone (02) 6207 8210 or email the Team Leader, Shirley-Anne McIntyre, at shirley-anne.mcintyre@act.gov.au For more information about the MHS-ID service model, read the article: Wurth P, Brandon S. The ACT Mental Health Service for People with Intellectual Disability, 10 years on. Australasian Psychiatry 2014; 22: 52-55.

Organisations, services and schemes

Name	Link and description
NDIS	
National Disability Insurance Scheme	http://www.ndis.gov.au/ The National Disability Insurance Scheme (NDIS) aims to work with local communities to improve inclusion of people with disability, including intellectual disability, and build awareness of disability. For individuals who meet the access requirements, information and referrals to support accessing community services and activities can be provided, including accessing current supports and making an individualised plan for the future. This plan may include assistance in accessing therapies, equipment, employment assistance and taking part in community activities. The NDIS provides disability support; this has no impact on income support such as the disability support pension.
Complex needs	
Multiple and Complex Needs Initiative (MACNI)	http://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. MACNI provides an effective and coordinated 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.

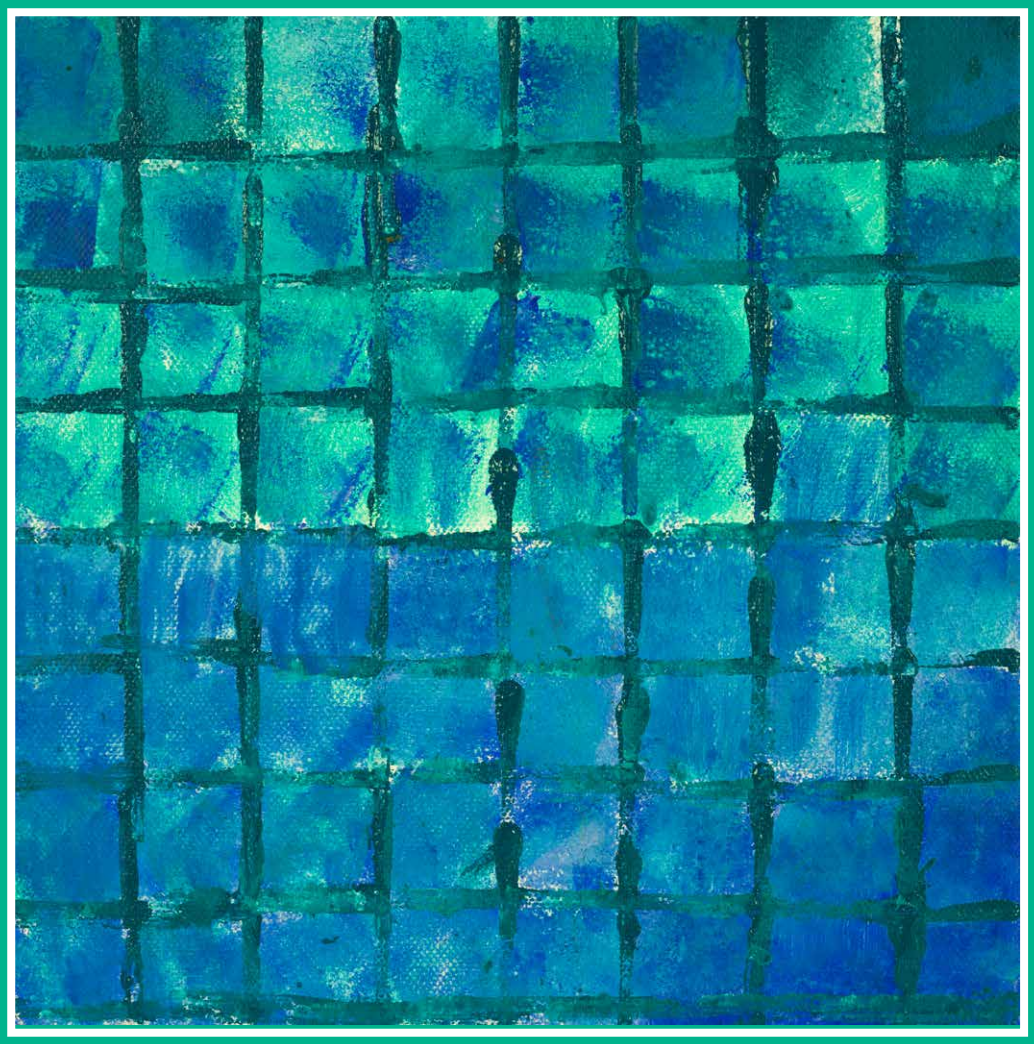
Name	Link and description
Transcultural mental health	
NSW Transcultural Mental Health Centre	http://www.dhi.health.nsw.gov.au/Transcultural-Mental-Health-Centre/Transcultural-Mental-Health-Centre-Home/default.aspx The Transcultural Mental Health Centre is funded by the NSW Government to work with people from CALD communities, health professionals and partner organisations across NSW. Services include development of multilingual mental health factsheets and provision of professional education and training on working with people from CALD backgrounds.
Translating and Interpreting Service (TIS National)	https://www.tisnational.gov.au/en TIS National is an interpreting service provided by the Department of Immigration and Border Protection for people who do not speak English and for services and businesses that need to communicate with their non-English speaking clients. Over the phone and on-site interpreting is provided.
Sexual health (and LGBTIQ)	
Family Planning NSW	https://www.fpnsw.org.au/ This website includes resources and information about sexual health issues, including those for LGBTIQ populations.
Rural and remote mental health	
Centre for Rural and Remote Mental Health	http://www.crrmh.com.au/ The Centre for Rural and Remote Mental Health is an initiative of the University of Newcastle and the NSW Ministry of Health. The Centre establishes partnerships with rural mental health stakeholders, conducts research, provides education, delivers and develops early intervention and support services to improve mental health outcomes for people living in rural and remote communities.
Guardianship Division, NSW Civil and Administrative Tribunal (NCAT)	http://www.ncat.nsw.gov.au/Pages/guardianship/guardianship.aspx The Guardianship Division conducts hearings to determine applications about adults with a decision-making disability who are incapable of making their own decisions, and who may require a legally appointed substitute decision maker.
Guardianship	
NSW Public Guardian	http://www.publicguardian.justice.nsw.gov.au The Public Guardian promotes the rights and interests of people with disabilities through the practice of guardianship, advocacy and education. The Public Guardian is a statutory official appointed by the Guardianship Division of the NSW Civil and Administrative Tribunal (NCAT) or the Supreme Court under the Guardianship Act 1987.
Human rights and anti-discrimination	
Australian Human Rights Commission	https://www.humanrights.gov.au/ An independent statutory organisation leading the promotion and protection of human rights in Australia.
United Nations Human Rights Office of the High Commissioner	http://www.ohchr.org/EN/Pages/WelcomePage.aspx The Office of the United Nations High Commissioner for Human Rights represents the world's commitment to universal ideals of human dignity, with a unique mandate from the international community to promote and protect all human rights.
Anti-Discrimination Board of New South Wales	http://www.antidiscrimination.justice.nsw.gov.au/ The Anti-discrimination Board of NSW promotes anti-discrimination, equal opportunity principles and policies throughout NSW.

Communication tools

Name	Link and Description
Guides	
Beyond speech alone: Guidelines for practitioners providing counselling services to clients with disabilities and complex communication needs	http://www.scopevic.org.au/shop/beyond-speech-alone-dvd-booklet/ This DVD and booklet provides guidelines for practitioners providing counselling services to clients with complex communication needs associated with a disability.
Easy English Writing Style Guide	http://www.scopevic.org.au/wp-content/uploads/2015/02/Clear-Written-Communications.-The-Easy-English-Style-Guide..pdf This booklet provides a range of guidelines to support the presentation of 'easy-to-read' information in accessible reports, brochures and flyers.
Scope Accessible Information and Easy English	http://www.scopevic.org.au/service/accessible-information/ Style guide and factsheets on Easy English and accessible information.
Your guide to: Communicating with people with a learning disability	https://www.mencap.org.uk/sites/default/files/2016-12/Communicating%20with%20people_updated%20(1).pdf This is a simple guide for communicating with people with an intellectual disability that includes links to resources
Your guide to: Communicating with people with profound and multiple learning disabilities	http://www.jpaget.nhs.uk/media/186401/Communicating_with_people_with_PMLD__a_guide__1_.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 an intellectual disability. The guides also contain tips on how to be a better communicator, and how to assist someone with an intellectual disability to get their message across.
Tools	
Key Word Sign	http://www.scopevic.org.au/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. Key Word Sign Australia supports children and adults with communication and language difficulties and provides resources to families, support persons and professionals.
Speakbook	http://www.speakbook.org/ Speakbook is an easy to use, easy to learn, communication tool for people who cannot speak or use their hands. With Speakbook, individuals can communicate using only their eyes.
The Hospital Communication Book	http://www.surreyhealthaction.org/downloads/Hospital%20Communication%20Book%20-%20version%202%20-%20web.pdf This booklet contains useful information about why people may have difficulties understanding or communicating, tips to help you improve communication, and pages of pictures you can use to assist communication.
Picture Communication Tool	http://www.picturecommunicationtool.com/ The Picture Communication Tool comprises sets of drawings that can be used within a medical setting with people who are unable to communicate verbally. The drawings are free to download and are ready for printing.

Resources for people with an intellectual disability and their family and support network

Name	Link and Description
Factsheets and information	
EasyHealth.org.uk Easy English resources	http://www.easyhealth.org.uk/categories/health-leaflets/ Freely downloadable pamphlets and videos in Easy English about a large range of health issues.
Foundation for People with Learning Disabilities publications	http://www.learningdisabilities.org.uk/publications/ Provides a range of resources for people with an intellectual disability, support persons and service providers.
NSW Council for Intellectual Disability Mental Health Easy Read Factsheet	http://www.nswcid.org.au/images/factsheets/ER6_MentalHealth.pdf An Easy read factsheet written by the NSW Council for Intellectual Disability on topics such as 'what is mental health', 'what are signs I need help with my mental health' and 'what can help me feel better'.
NSW Council for Intellectual Disability Easy Read Health Factsheets	http://www.nswcid.org.au/health-fact-sheets.html A range of health factsheets are available for individuals with an intellectual disability, including topics such as visiting the doctor, signs of mental ill health, and signs of sickness.
NHS A Picture of Health Factsheets	http://www.apictureofhealth.southwest.nhs.uk/mental-health/ Easy read factsheets on mental health (plus a range of other topics and resources).
Royal College of Psychiatrists Easy read resources	http://www.rcpsych.ac.uk/mentalhealthinfo/problems/learningdisabilities.aspx Easy read pamphlets providing information for patients about common psychotropic medications.
Health passports	
Communication Passport for Accident and Emergency	http://widgit-health.com/download-files/aande/2013/A-E_Communincation_Passport_2013.pdf The Communication Passport for Accident and Emergency is an Easy English document that patients and their support persons can fill out, ready to take to hospital when necessary, which informs health staff about their medical history, important information before carrying out interventions, and their likes and dislikes. It includes information such as what to do if the individual is anxious, and how to best communicate with them.
Health Passport	https://www.choiceforum.org/docs/stocp.pdf A similar, more detailed Health Passport that can be taken to medical appointments which contains more questions about mood and what can help the individual to feel calm.
Supported decision-making	
ADACAS Support my Decisions website	http://www.support-my-decision.org.au/ This Easy read website helps people with an intellectual disability to make supported decisions. It contains tools and information on how to make decisions, and how to support someone to make decisions.
Additional information for family and support persons	
The Mental Health Service Delivery Framework in NSW Factsheet	http://www.sfnsw.org.au/ArticleDocuments/788/MHS%20NSW.pdf.aspx Produced by the Mental Illness Fellowship of Australia Inc., this factsheet for family and support persons provides a summary of how mental health services are structured in NSW.
The Mental Health Legal Framework in NSW Factsheet	www.sfnsw.org.au/ArticleDocuments/788/MHLF%20NSW.pdf.aspx Also produced by the Mental Illness Fellowship of Australia Inc, this factsheet for family and support persons outlines the Mental Health Act and protective bodies in NSW.



Shai de Vletter-Sont, Blue Poodle
Acrylic on canvas, 255mm x 255mm
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Shai de Vletter-Sont, SPINE
Acrylic on canvas, 300mm x 405mm
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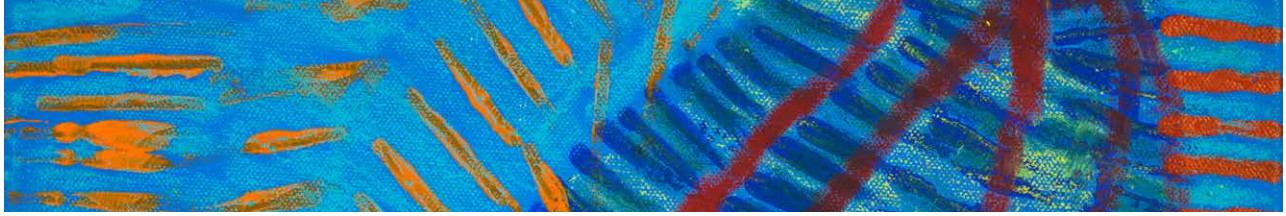
Appendices



APPENDIX A

Glossary

ABC chart

An Antecedent Behaviour Consequence (ABC) chart provides a method for recording details about an observed behaviour. Details recorded include the setting, time and frequency of behaviour, what happened just before the behaviour, a description of the behaviour, and the consequence of the behaviour.

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.

Augmentative and alternative communication

Augmentative and alternative communication is a range of techniques that can be used as an alternative or addition to speech, such as picture systems or signing.

Challenging behaviour

Challenging behaviour (also known as 'behaviours of concern') is most commonly defined as a "behaviour 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 deny access to the use of ordinary community facilities". [43]

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). [25] All intellectual disabilities are developmental disabilities, but not all developmental disabilities are associated with an intellectual disability.

Diagnostic overshadowing

Diagnostic overshadowing is when a person's symptoms of mental or physical ill health are overlooked and are incorrectly attributed to being part of the person's intellectual disability. [44]

Easy read

A style of writing that has been developed to provide simple, understandable information to people with an intellectual disability. It uses clear formatting and pictures to aid understanding. Short lines of text are justified on the right, while pictures are placed on the left of the page. It is similar to the Easy English style of writing. However, Easy English documents do not have such strict formatting requirements, and are used for anyone with low English literacy.

Integrative interventions

Integrated interventions take a coordinated approach utilising different treatment methods from different dimensions including developmental, biological, psychological and social. [45] This approach also includes working with other key organisations who are delivering related intervention to the person to ensure that they are complimentary.

Intellectual disability

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 diagnosis be based on the severity of deficits in adaptive functioning. An intellectual disability is diagnosed using a combination of standardised intelligence tests, such as IQ scoring, and assessments of adaptive functioning. The severity of intellectual disability can be classified as mild, moderate, severe or profound. The DSM-V uses the term "intellectual disability" to replace the term "mental retardation". Intellectual disability may co-occur with other developmental disorders and other mental disorders.[46]

Mental health

The World Health Organisation defines mental health as "a state of wellbeing in which the individual realises his or her own abilities, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to his or her community". [47]

Multi-modal assessment

A multi-modal assessment covers biomedical, psychological and social domains and involves input from a range of people. This approach allows for the mental health professional to gain an in-depth view of the person's physical health, mental health, functional and behavioural profile. [48]

Key partners in a multi-modal assessment may include the person, their support network (including family members and other paid and unpaid support networks), mental health professionals, general practitioners, disability professionals, and behavioural specialists etc.

Person-centred approach

A person-centred approach has at its heart the principles of equality, choice and inclusion. Implementing a person-centred approach means putting the person with the intellectual disability at the centre of planning and decision-making about their own support and services.

Person first language

This style of communication places the person first rather than their disability or impairment and describes what the person has, not who they are. The use of this language is important because it influences community attitudes and the way in which people with a disability are viewed within our community.

Self-determination

Self-determination is a situation where people with an intellectual disability have "the skills, opportunities and supports to act as causal agents in their lives" (p.107). [49]

Supported decision-making

Supported decision-making is a way of making sure that everyone can exercise their right to make their own decisions. It involves a "person with disability and one or more trusted family members, friends or supporters. These people help the person with disability to make their own decisions about their life". [50]

APPENDIX B

Overarching clinical principles

Mental health services for people with an intellectual disability must be supported by a human rights framework that encourages the inclusion and independence of people with an intellectual disability. The Mental Health Statement of Rights and Responsibilities states that Australian governments have a responsibility to support the development of high quality, recovery-focused and evidence-based services. [51] These services should be integrated with mental health, general health and disability services. The guiding principles are summarised below. [52] The following principles come from the Framework and The Guide.

Rights

A human rights framework in health care identifies people with a disability as having a right to health and health care. The United Nations Convention on the Rights of People with Disabilities (CRPD), [6] to which Australia is a signatory, obliges all levels of government to ensure that people with disabilities have the right to the highest attainable standard of heath without discrimination. For people with an intellectual disability and co-occurring mental ill health, this means ensuring:

- the same range and quality of free or affordable mental health care that is available to those without intellectual disability;
- services that address comorbid mental health conditions, and services that assist in preventing secondary disabilities;
- accessible mental health services that are provided as close as possible to people's communities, including rural and remote areas; and
- a system which promotes high standards, and prevents discriminatory denial of mental health care. [6]

Inclusion

As people with an intellectual disability have the right to fully participate in all aspects of community life, they should also be able to access all components of mental health services, including mainstream and specialised services. This also extends to accessing population health programs aimed at preventing mental disorders. For this to be achieved, some people with an intellectual disability will require support, and for accessible materials about mental health to be provided. Mental health providers may need to adjust their practices to ensure inclusion, such as adjusting communication. A readiness to engage and include family members and support networks in the planning, implementation and review of treatment programs is also vital. [53] Mental health services and staff need to promote and facilitate inclusiveness of people with an intellectual disability, and be guided by positive and non-discriminatory attitudes. This may include their involvement as peer supporters and participation in the designing and evaluation of service improvement activities.

Person-centred approach

A person-centred approach to mental health maximises the involvement of the person with an intellectual disability in decision-making, rather than viewing them as passive recipients of care. The individual is seen as central to any decision made regarding their mental health (in line with their age and capacity), and throughout the preparation of their care plan. This approach tries to understand the situation from the person's own perspective, determining what is important to them. Family and support persons should also be consulted where appropriate, but it should be recognised that their opinions may be different from the person with an intellectual disability. Therefore, it is critical that mental health professionals work directly with the person with an intellectual disability and respect their wishes as far as possible. Service providers in both health and disability networks can be seen as partners, working together to provide a cohesive system of person-centred mental health supports. [53, 54]

Promoting independence

Mental health providers should recognise the autonomy of people with an intellectual disability, and aim to maximise independence (taking into account age and capacity). Mental health professionals should also support decision-making, assisting people with an intellectual disability to understand, consider and communicate their choices (see 3.2 Informed consent and supported decision-making section).

Evidence-based

Choices that mental health professionals make should be guided by the best available evidence, which can help to achieve the best possible mental health outcomes.[26] This means that mental health providers should seek 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 intellectual disability. If there are no specific guidelines or information available, best practice can include interpreting results of studies in the general population, and applying them where appropriate. Mental health professionals can also contribute by sharing new and innovative interventions they undertake within their networks.

Recovery-orientated practice

The National Standards for Mental Health Services [26] state that recovery for individuals with mental ill health means "gaining and retaining hope, understanding of one's abilities and disabilities, engagement in an active life, personal autonomy, social identity, meaning and purpose in life and a positive sense of self". Recovery-orientated mental health practice endeavours to support individuals to build on their strengths so that they can take as much responsibility for their lives that is possible at the time. The individual is seen as an expert in their own life and lived experience, while the mental health professional can share expertise in treatment options. [27]

For people with an intellectual disability, recovery-orientated practice relates specifically to mental health rather than support for their intellectual disability. Rather than merely ameliorating mental disorders, recovery-orientated practice focuses on providing long-term holistic care and ongoing wellbeing. Recovery outcomes are specific to each person, and include quality of life and social inclusion.[26] As individuals with an intellectual disability may require more complex supports, recovery-orientated practice may require greater effort be made for this group. In practice, this may involve a thorough and appropriate mental health assessment and collaboration between health, social, and disability services, along with the person with an intellectual disability and their support network. This collaboration can help to ensure that the service provided is consistent with the individual's values and goals.

Strengths-based: Empowering the person, their family and support networks

It is vital that mental health services take strengths-based approaches when working with people with an intellectual disability. This is due to the fact that this group are often faced with a deficits-based approach, with the focus being on their impairments and limitations, which can be a risk factor for mental ill health. The strengths of the individual, their family and support networks should be considered by mental health professionals. This in turn can enhance mental health outcomes and maintain mental health and wellbeing over the long term.

Flexible

Mental health professionals who have worked extensively with people with an intellectual disability have found that taking an open minded approach and trialling different approaches to support the person (as far as it is safe to do so) results in the most positive outcomes for the individual. This approach also leads to a more positive therapeutic dynamic. A flexible approach may include using a different style for the initial assessment, modifying language so it can be understood by all parties, using alternative communication methods and speaking to people that you would not usually engage with.

Proactive

Initially there can be confusion regarding the role that different services and professionals play when working with people with an intellectual disability. This can delay the person's access to mental health care and other essential services, which can negatively affect their mental health and wellbeing. Taking a proactive approach to supporting a person with disability can enable early access to essential services and supports for the person, improve mental health outcomes, and enhance professional relationships.

Multidisciplinary and cross agency

People with an intellectual disability may have multiple individuals in their support network, and they can face challenges when they do not work collectively. As a mental health professional, you can enhance the quality of care and possible outcomes by working collaboratively with the person's support network. Seeking out additional supports from other disciplines and services may also be required to meet the person's mental health needs.

APPENDIX C

Additional key issues

This appendix outlines a number of additional key issues that mental health professionals should consider when working with people with an intellectual disability, including challenging behaviour, preventative health care, legal and ethical issues, and special considerations for different populations.

1. Challenging behaviour and mental ill health

Challenging behaviour is commonly defined as:

> *"behaviour 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 deny access to the use of ordinary community facilities."* [43]

Examples of common challenging behaviours that people with an intellectual disability exhibit include oppositional behaviour, aggression towards others or objects, repetitive and stereotyped behaviours/ actions, inappropriate behaviour e.g. sexual behaviours, and withdrawal from activities. These behaviours, resulting from interactions between biological, environmental, social and psychological influences, can have significant effects on the individual and their family and support persons e.g. social exclusion, stress, and overuse of psychotropic medication. [17]

Challenging behaviour may be due to pain, or symptoms of mental or physical ill health. Treatment of the mental or physical health problem is then paramount, rather than merely imposing restrictions that make it harder for the behaviour to occur, leaving the cause untreated. Challenging behaviour can be caused by various psychiatric disorders, including depression, anxiety, mania or psychosis, and can also place individuals at risk of developing psychiatric disorders due to the negative impact of such behaviours.

A multidisciplinary approach is important for managing challenging behaviours. When there has been a new onset or rapid escalation, or severe challenging behaviour that does not abate, a full mental health assessment is required. If a mental disorder is detected, its treatment will likely lead to a significant improvement in behaviour. For individuals with severe, ongoing challenging behaviours that are not thought to be caused by mental ill health, people will still require ongoing support from mental health services to i) monitor for the development of any future mental disorders as they will likely be at high risk and ii) allow for the prescription of psychotropic medication where appropriate.

Management of challenging behaviour requires the input of both health and disability services, and includes developing a detailed behavioural support plan after a thorough assessment including psychiatric causes. While management is chiefly behavioural, psychotropic medication may be prescribed when there is a defined mental disorder, or if the individual has severe challenging behaviour that has not responded to behavioural treatment or other interventions.

Vignette 10: Challenging behaviour

Luke is an 11 year old boy who has a moderate intellectual disability and autism spectrum disorder. He is highly mobile, is 135cm tall and weighs 64kg. Luke has a few spoken words but his primary means of communication is key word sign and natural gesture. Luke lives with his mother, and six year old sister. The family have no contact with Luke's father. His mum reports feeling frightened of Luke when he is in a rage, and worries about her daughter's safety, especially when Luke gets bigger and stronger. Over the past two years, Luke has been receiving increasing amounts of care at a children's respite unit. Both at home and at the respite centre, Luke's family and support persons are finding it difficult to manage his challenging behaviours, which include screaming and crying; hitting, pinching and eye gouging of other children; and breaking and throwing objects. Luke's case manager contacted Luke's mother and other service providers to suggest a meeting to develop a standard response to critical incidents. A working definition of Luke's behaviour was developed, and the insights of all the participants summarised. Strategies to manage Luke's behaviour were discussed, keeping in mind that they needed to focus on ending the crisis as quickly and safely as possible, were legal and ethical, were least intrusive and restrictive as possible, respected the dignity of all involved, and were realistic given resources. The strategies decided on included:

- *For hypersensitivity, decreasing arousal by turning off lights, turning down/off music, offering a weighted blanket.*
- *Helping Luke to recognise his escalating arousal by using a child-chosen metaphor e.g. 'Luke you're like a fast horse now, it's time for…..'.*
- *To reduce Luke's agitation, providing Luke with information about any upcoming changes (via key word sign).*
- *At the height of crisis, removing others.*
- *Ensure support persons wear appropriate clothing and footwear and limit jewellery.*
- *To reduce risk, modifying the physical environment e.g. move or secure things that can be thrown or smashed; provide a door through which family/staff can withdraw.*
- *Providing low-key positive feedback on Luke's attempts to calm himself.*
- *Training and opportunities for practice for family and staff; having opportunities for review.*

The implementation of the plan led to significant improvements in Luke's emotional and behavioural wellbeing. The number of reported incidences has reduced, and they are shorter and less severe. Consequently, his relationships with others have improved.

2. Preventative health care

As individuals with an intellectual disability may have difficulty communicating, they may not voice concerns about physical and mental ill health, request vaccinations, or ask for regular screening tests such as cholesterol testing. An annual health check by a GP improves the identification and management of health conditions. It also assists in health promotion and prevention, including maintenance of mental health.

Mental health

People with an intellectual disability have the right to participate fully in all aspects of community life, and should have access to all elements of health and mental health services, including population health programs aimed at the prevention of mental disorders. Preventative mental health programs aimed at people with an intellectual disability largely do not exist at present. Therefore, some individuals with an intellectual disability will require the provision of modified accessible materials about mental health (such as Easy read documents).

Health promotion and prevention can be improved for people with an intellectual disability from the primary health care level up, with clinicians carrying out regular screening for common conditions such as depression and anxiety, and providing information about preventing and recognising mental illness for those at risk.

Exercise and nutrition

Two areas that are closely related to physical and mental health are exercise and nutrition. For individuals who are ambulant, normal exercise recommendations and guidelines apply. For those who have mobility issues, referral to an allied health professional (e.g. exercise physiologist or physiotherapist) can be valuable to develop a modified exercise program.

Weight issues are more prevalent in people with intellectual and developmental disability than in the general population (both being underweight and obese). Both conditions have serious health consequences, and should not be thought of as inherent to the person's disability. Similarly, smoking is a significant concern for people with an intellectual disability, and advice, support and education should be provided in accessible formats. [25]

3. Legal and ethical issues

Ethical practice, conducted within legal frameworks is paramount for all mental health clinical practice. However, it is especially important to consider these issues for people with an intellectual disability as there can be greater complexity. Individuals with an intellectual disability may face less equitable care, lack the capacity to consent to treatment, and have support persons closely involved in their care, which raises issues relating to the right to privacy. Therefore it is important for mental health professionals to be familiar with guidelines and legislation relating to these issues. For mental health professionals practicing in NSW Mental Health Services, it is important to be aware of current NSW Health policy and guidance on topics such as informed consent and various legal and ethical issues, the NSW Mental Health Act, and guardianship.

The Intellectual Disability Mental Health e-learning module on Legal and ethical practice (Module 9) outlines the main legal and ethical issues relating to clinical practice for people with an intellectual disability, and is a useful starting point to gain knowledge regarding this area.

Legal and ethical clinical practice is examined in the module, and includes the following topics:

- the human rights of people with an intellectual disability;
- the right to equality and freedom from discrimination;
- the right to respect for physical and mental integrity; and
- the right to privacy.

4. Special considerations for different populations

Aboriginal and Torres Strait Islander people(s)

Aboriginal and Torres Strait Islander people experience significant physical and mental health inequalities compared to the general Australian population. A range of complex social and historical factors increase health risks for Aboriginal and Torres Strait Islander people and reduce access to services. The many disadvantages faced by people who identify as Aboriginal and Torres Strait Islander are further compounded for those who also have an intellectual disability. This population often experience very poor social outcomes such as over-representation in the criminal justice system, and poor mental health outcomes. Mental health professionals are encouraged to undertake Aboriginal and Torres Strait Islander cultural competence training (e.g. HETI Online Aboriginal Culture - Respecting the Difference) and further professional development on the complex issues faced by Aboriginal and Torres Strait Islander people with an intellectual disability.

Culturally and Linguistically Diverse populations

According to the Australian Bureau of Statistics 2011 census data, 31.4% of people living in NSW were born overseas. [55] While there is limited evidence regarding the mental health status of culturally and linguistically diverse (CALD) Australians, it is known that people from CALD backgrounds, including those with an intellectual disability, access fewer mental health services than the general population and are over-represented in acute tertiary services. Factors that may influence this trend include language barriers and the mental health stigma that exists within some cultures. There are useful services that support organisations to provide mental health services to people from a range of cultural and linguistic backgrounds (e.g. The Mental Health in Multicultural Australia Project, NSW Transcultural Mental Health Centre and the Translating and Interpreting Service). These services can assist mental health professionals to communicate effectively with people from CALD backgrounds.

Lesbian, Gay, Bisexual, Transgender, Intersex, and Queer (LGBTIQ) people

While people with an intellectual disability may face barriers to making choices in relation to their own sexuality (e.g. due to living in group accommodation with a lack of privacy and a lack of opportunities to socialise), [56] many have long-term relationships, including those other than heterosexual ones. [57, 58] People with an intellectual disability have a right to information about sex, and a right to sexual expression. [56] While individuals who have an intellectual disability still face discrimination, [59] those who also identify as LGBTIQ can experience yet another source of discrimination, [60] which may be compounded if they also experience mental ill health. Providing a positive environment and support is vital, including respecting the values and attitudes of the individual, providing age-appropriate information, and allowing individuals to openly discuss sexual issues.

Mild intellectual disability

Assessment and treatment of people with mild intellectual disability and co-occurring mental ill health is often the same as for the general population. However, barriers to services still exist for this population group. Therefore, it is important for mental health professionals to be aware of signs that an individual may have a mild intellectual disability, so they can ensure (where appropriate) that:

- the environment and communication style used is appropriate to the person with an intellectual disability;
- the service is inclusive for people with an intellectual disability (e.g. providing information brochures in Easy read);
- the clinical service pathway for people with an intellectual disability is utilised; and
- if they have them, the person's disability services and other supports are engaged.

See section 3.1 Assessment process for ways to recognise intellectual disability. As noted previously, some individuals with borderline or mild intellectual disability may not choose to disclose this due to concerns about discrimination or stigma, or may not identify as having a disability. During assessment and treatment sessions, individuals with a mild intellectual disability may take longer to understand concepts, may ask for information to be repeated, have difficulty with abstract concepts, and may not make expected progress with psychological therapies such as cognitive behaviour therapy (CBT).

In general, individuals with mild intellectual disability will be able to participate in family life and contribute to their community, have important relationships in their life, work in either open or supported employment, may read and write, may live and travel independently with some support, and may marry and raise a family. [61]

Complex needs: multiple and complex disability needs

People with an intellectual disability and complex needs include those who have severe intellectual disability, and people with an intellectual disability that have other complex issues such as physical disabilities/comorbidities, severe mental illness, substance use disorders or challenging behaviours. People with an intellectual disability and complex needs are generally not adequately supported within mainstream mental health or disability services. In the current service system, there are many service gaps and insufficient inter-service coordination. A person with an intellectual disability and complex needs presenting with a mental health disorder may need to be referred to a specialist IDMH professional or team. Training for the mental health workforce in developing and utilising appropriate referral pathways and supports is required.

Forensic populations

Individuals with an intellectual disability and mental ill health are at a higher risk of engaging in offending behaviours than the general population, which means they are overrepresented in courts [62] and gaols. [63-65] Research suggests that offenders who have an intellectual disability are more likely to be unemployed, uneducated, underprivileged, a member of an indigenous minority, have experienced neglect or abuse in childhood, and experience behavioural and/or psychiatric disorders. [66, 67] It is estimated that almost 13% of the prison population in NSW have an intellectual disability. A considerable proportion of offenders with an intellectual disability also have a comorbid mental disorder. [63]

Adults with an intellectual disability and a cognitive disability in particular are vulnerable to repeated encounters with the criminal justice system without appropriate support. [63] For individuals on probation, between 6-19% show signs of an intellectual disability, but very few have had any contact with intellectual disability services. [68] Specific resources and expertise are required to meet the needs of this population, in consultation with corrections and forensic mental health systems, and departments such as the NSW Department of Family & Community Services.

People living in rural and remote areas

People living in rural and remote communities face a range of additional barriers to accessing mental health care. These include having reduced access to mental health professionals, increased stigma related to mental health (in some areas) and limited public transport to attend services.

To enable mental health service providers to reach people with an intellectual disability and co-occurring mental ill health, an industry-wide increase in the use of, and access to, Telehealth and e-health services is needed. Examples of effective use of e-health and Telehealth for providing mental health services include the Mental Health Emergency Care – Rural Access Program, mindhealthconnect and e-headspace.

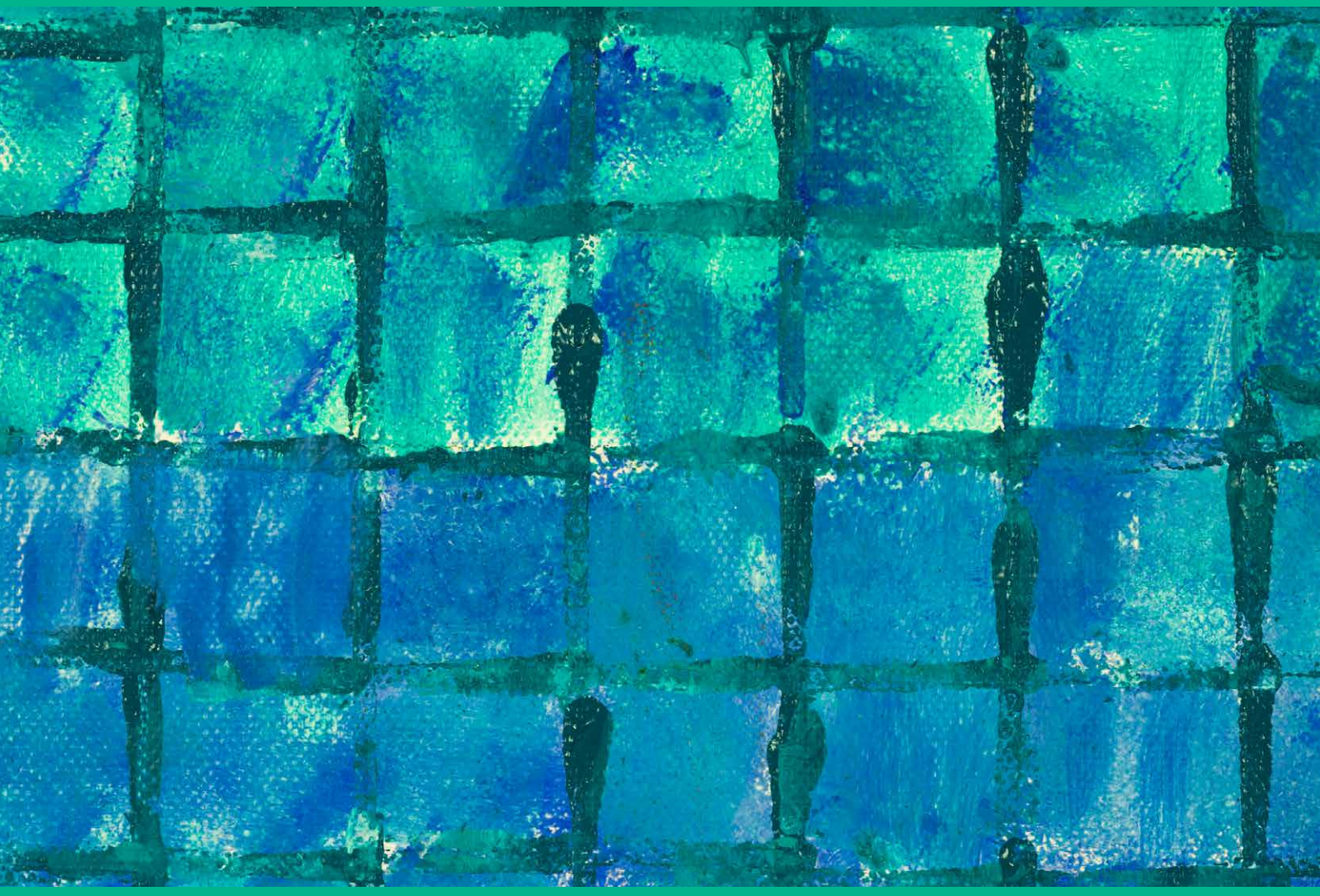
Vignette 11. Intellectual disability mental health in forensic settings

A forensic psychiatry trainee was asked by the court to assess an 18 year old man, James, who had been charged with arson in a local park. The man had prior arrests for larceny. The psychiatry trainee had some experience with intellectual disability, but sought advice from an experienced supervisor. Upon assessment, the psychiatrist noted from previous records that James had an IQ of 53, a history of depression with psychotic episodes, and had used cannabis heavily for four years. James had shown significant behavioural difficulties throughout childhood, and had spent some time in state care. Prior to referral he was not receiving consistent mental health or disability services. In his report the psychiatrist detailed that a custodial sentence would potentially result in poorer mental health and victimisation of the accused, as is common for those with intellectual disability in the criminal justice system. It also contained recommendations to the court on necessary adaptations to the court process (such as a support person to help James understand the complex court proceedings). Taking into account James' mild-moderate intellectual disability, mental health issues, and background, the psychiatrist recommended that he was unfit to stand trial. A jury consequently agreed that James was not fit to stand trial, so a special hearing took place. The defendant was found to have a mental impairment, so the Court entered a verdict of not guilty. The Court made a non-custodial supervision order, with James ordered to attend an arson intervention program and see a psychiatrist regularly. A case worker was assigned, who coordinated these interventions, along with connecting James to additional disability services. With consistent care, James' mental health improved, and he learnt ways to control his fire setting behaviour, with no recidivism two years later.

APPENDIX D

Advisory group members

Member	Position	Organisation
Ms Bernadette Dagg	Interagency Manager, Specialist Programs Team, MH-Children and Young People	Hosted by the Sydney Children's Hospitals Network, Westmead (Mental Health Branch), NSW Ministry of Health
Assoc Prof David Dossetor	Senior Staff Specialist, Director for Mental Health, Sydney Children's Hospitals Network	NSW Health
Ms Claire Eagleson	Project Manager	Department of Developmental Disability Neuropsychiatry, School of Psychiatry, UNSW Sydney
Ms Christine Flynn	Senior Policy Officer	Mental Health Branch, NSW Ministry of Health
Dr Roderick McKay	Clinical Advisor, Older People's Mental Health Policy Unit	Mental Health Branch, NSW Ministry of Health
Ms Tania Skippen	Associate Director, Specialist Programs, MH-Children and Young People	Hosted by the Sydney Children's Hospitals Network, Westmead (Mental Health Branch), NSW Ministry of Health
Prof Julian Trollor	Chair	Chair of Intellectual Disability Mental Health and Head, Department of Developmental Disability Neuropsychiatry, School of Psychiatry, UNSW Sydney
Ms Jessica Walsh	Project Officer	Department of Developmental Disability Neuropsychiatry, School of Psychiatry, UNSW Sydney
Ms Janelle Weise	Project Officer	Department of Developmental Disability Neuropsychiatry, School of Psychiatry, UNSW Sydney



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