

# A Core Capability Framework

**For working with people  
with intellectual disability  
and co-occurring mental  
health issues**



## Acknowledgements

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## 1.0 Introduction

People with intellectual disability are significantly more likely to develop a co-occurring mental health issue than the general population due to biological, social or psychological factors. The impact of this can be significant and often difficult to detect. For example, assessment tools usually require verbal questioning of a target group that experiences significant communication and cognitive processing issues.

This means that adaptive assessment measures need to be utilised such as observations and feedback from support workers, carers, family and significant others that may include the exploration of different potential influencing factors. Furthermore, behavioural changes may be attributed to symptoms of intellectual disability rather than the possibility of a mental health issue (diagnostic overshadowing) (Department of Human Services, 2010).

People with intellectual disability and a co-occurring mental health issues range from those with low support needs or mild disability through to people who have high and multifaceted support needs. Service provision for this group of consumers is broader than that of mental health and disability providers alone and crosses a wide range of human service and health sectors. They may require multiple services and supports due to the complexity in diagnosis and treatment and the skills required to appropriately support and manage their needs. It often involves a cross-sectoral or a multi-disciplinary approach that requires pre-planning and time to manage service collaboration and inter-agency referral processes. The role of the family and carers in supporting people with intellectual disability and a mental health issue and how we work appropriately and respectfully alongside them as service providers will also greatly improve outcomes.

This Framework has been developed for a broad workforce with the aim of achieving access to high quality mental health services and a seamless pathway for people with intellectual disability and a co-occurring mental health issue, their carer, family members or guardians. It is intended for use by Service Providers working with people with intellectual disability who have a diagnosed mental illness and those who require assessment because their behaviour suggests they may have a mental health problem.

### 1.1 Definitions

The problem with working with definitions is that it sets a boundary and framework around the 'things' that are 'studied'. However, in the area of intellectual disability, definitions and labels are also a way of determining whether a person is eligible to gain access to services. The definition of intellectual disability is therefore much more than a point of academic interest, but of major importance to both service providers and persons with intellectual disability and their families (Snoyman, not cited). People with intellectual disability may find the label useful in making sense of their world but, at the same time, the term may be a stigmatising experience. For this reason, trying to group all people under the definition to fit this particular framework has had its difficulties, yet does not diminish those who fall outside the formal definition or are borderline in meeting the criteria and who will experience challenges particularly where mental illness or mental health issues exists.

### 1.1.1 Intellectual disability

A person is said to have an **intellectual disability** if they have an intelligence quotient (IQ) score below 70, onset before the age of 18 years, and have significant difficulties with adaptive functioning (e.g. daily living skills, understanding concepts, communicating and taking part in social activities). It is typically described in terms of its affect or the person's support needs: mild, moderate, severe or profound based on the level of impairment. Generally speaking, the more severe the impairment, the higher the level of support required from health and community service providers.

For a more comprehensive definition refer to the Glossary (refer to section 6.0). There are other groups of people who experience difficulties with processing instructions and with daily living skills and who may not meet the criteria required to be diagnosed with intellectual disability. However, these people may also have co-occurring mental illness or be at risk of increased mental health problems. This includes:

- those with an acquired brain injury or cognitive impairments due to lead poisoning, chronic alcohol/drug use or other illness onset after the age of 18;
- people with Autism Spectrum Disorder who do not have intellectual disability; and
- people with a low or borderline IQ score above 70.

The Framework will be applicable to these people, but it does not go into the depth required to cover all aspects particular to their needs.

### 1.1.2 Mental illness

A **mental illness** is a health problem that significantly affects how a person thinks, behaves and interacts with other people. It is diagnosed according to standardised criteria. It is a clinically diagnosable disorder that significantly interferes with an individual's cognitive, emotional or social abilities. The most common types of mental illnesses include schizophrenia, depression, bi-polar disorder, anxiety, and eating disorders.

### 1.1.3 Mental health issue

A **mental health issue** also interferes with how a person behaves, thinks and feels but to a lesser extent. However, a mental health problem can develop into mental illness if not dealt with (The Department of Health, 2007).

Just as the risk of mental health issues is high for people with intellectual disability, there is evidence that people with Acquired Brain Injury (ABI) and Autism Spectrum Disorder and other cognitive impairments, are also more at risk of developing mental health issues.

## 1.2 Children with an intellectual disability and mental health issues

The Framework has primarily been developed for adults with intellectual disability and co-occurring mental health issues and, while still applicable, does not take into account the additional attributes, skills and knowledge required when working with children, including developmental perspectives and the role of the family.

## 1.3 Carers and guardianship

A carer refers to a person who provides unpaid care and support to family members and friends who have a disability, mental illness, chronic condition, terminal illness, an alcohol and other drug issue, or who are frail aged.

It is important to distinguish the difference between carers under the definition above as opposed to paid support workers who can frequently be referred to as 'carers' in the disability sector. A carer under the *Carers Recognition Act 2004* is distinguishable from a paid support worker as they have a personal, ongoing relationship with the individual requiring care, and provide assistance and support as part of the relationship they have with the individual for whom they provide care. Carers have a number of rights under both State and national legislation.

A formal guardian is also distinguishable from carers and/or family members as they have formalised legal rights to act and make decisions on behalf of another person, as is consistent with the *Guardianship and Administration Act 1990*. An individual may have more than one person acting as their Guardian. Individuals who are in such a role may be a carer however some Guardians may only have a decision making role.



## 2.0 Framework development process

### 2.1 Consultation-advisory group

The Western Australian Council of Social Service (WACOSS) worked closely with the National Disability Service (WA) and the Western Australian Association of Mental Health (WAAMH) to undertake consultation with their respective sectors as well as assistance in writing the Framework. We also acknowledge the Developmental Disability Council WA who coordinated the Consumer and Family and Carer feedback and whose experience and knowledge in this area has been invaluable.

A project advisory group was established to provide input and guidance into the development of this resource. Advisory Group members included the following:

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Delese Betti	Systemic Advocacy and Policy Officer, Carers WA
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Nathan Gibson	Chief Psychiatrist, Office of the Chief Psychiatrist
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Shauna Gaebler	CEO, Consumers of Mental Health WA
Trevor Blackburn	Manager South West Services, Richmond Fellowship of WA
Tricia Dewar	Principal Disability Health Coordinator Disability Services Commission



## 2.2 Service provider consultation

WACOSS held a consultation session with Service Providers to seek input on the skills and knowledge essential to supporting people with co-occurring intellectual disability and mental health issues; the difficulties and challenges specific to working with this group of people; and examples of good service models and practice. A total of 43 registrations were received with representatives from government, public services (hospitals, WA Police, justice) and community services attending.

Key issues drawn from these discussions included: the importance of collaboration; holistic models of care; and improved referral systems. Challenges included: the high likelihood of misdiagnoses; case loads and waiting times for assessments; after hours care; and the need for a coordinated or specialist unit to provide advocacy, information, coordination and support. The need for ongoing training due to staff turnover and changing roles and skill sets within the sector was also seen as important.

## 2.3 Consumer and family/carer feedback

In the development of this document the Developmental Disability Council of WA invited carers and family members of people with intellectual disability and co-occurring mental health issues to a discussion forum to hear their perspectives on what good service might look like. The following four questions were asked:

- Question 1      What would you like health and allied health professionals to understand about the challenges for you and your family member?
- Question 2      Thinking about examples of when things have gone badly, and times when things have gone well, what do you think good service provision looks like?
- Question 3      What kinds of challenges do you face when it comes to supporting your family member/person you care for?
- Question 4      Which other kinds of knowledge and understanding do you think should be part of the training for people who will support people with co-occurring intellectual disability and mental health problems?

Nine main themes emerged from the responses. The group expressed the view that good services have training in and know how to:

1. Support family and carer wellbeing;
2. Support the decision making capacity of families and carers;
3. Support the wellbeing of the person;
4. Support the person's safety, decision making and dignity of risk;
5. Communicate very effectively on a number of levels;
6. Be person-centred;
7. Be flexible and accessible;
8. Understand the purpose of, and administer, medication; and
9. Recruit, manage and supervise staff effectively.





## 3.0 Background

### 3.1 Supporting people with intellectual disability and a mental health issue

There is a growing awareness in Australia of the concerns involved in supporting and treating people with intellectual disability and co-occurring mental health issues. This has led to the publication of [\*Accessible Mental Health Services for People with an Intellectual Disability: A Guide for Providers \(The Guide\)\*](#). Reference to people with intellectual disability and co-occurring mental health issues was also included in “*The Review of the Admission or Discharge and Transfer Practices of Public Mental Health Facilities/ Services in Western Australian, July 2012*” by Professor Stokes (The Review). The Review refers to the complexities of life for people with intellectual disability and a co-occurring mental health issue including the vulnerability of this group, and the service gaps associated with their management and treatment within the health care system in Western Australia.

### 3.2 The past

It was only 40-50 years ago that people with either intellectual disability or mental illness were segregated from society and institutionalised. Both groups were labelled as having an ‘untreatable disability’ and were likely to spend the rest of their lives disenfranchised.

In the 1960s and 1970s improved treatments for psychiatric disorders and the Social Role Valorisation (SRV) movement stimulated the deinstitutionalisation of people with disability in Australia into the 1980’s. Delineation developed between disability and mental health services and when people were leaving the institutions, a determination had to be made around which was the primary disability for the purposes of referral to either a disability or a mental health service.

Over time, the disability and mental health sectors have continued to develop separately resulting in a divergent workforce. Staff tend to be trained in either intellectual disability or psychiatric/mental illness and experience difficulties when the two co-exist, despite the high prevalence. (Victorian Dual Disability Service, 2001).

This service separation has largely remained today despite an overlap between the two conditions: both may result from brain dysfunction leading to disturbances in thought, behaviour and emotion (Victorian Dual Disability Service, 2001) and until recently there has been little research undertaken into the prevalence of mental health issues in people with intellectual disability.

### 3.3 Recovery and person-centred models of care

There are two key concepts shaping policy nationally in the Mental Health and Disability sectors today: **recovery** and **personalisation/person-centredness**.

Recovery has its origins in the mental health consumer movement and is underpinned by four principles: finding and maintaining hope; re-establishing a positive identity; building a meaningful life; and taking responsibility and control (Commonwealth of Australia, 2013).

Underpinning recovery is the development of positive relationships across all sectors of life, including an improved sense of self, belonging, connection and relationships to others. This is often developed in part through the improvement of relationships with significant others such as carers, family and friends.

This recognition leads to a growth in understanding and more effective engagement. All these factors can help to empower people with intellectual disability and/or mental health issues to develop an increased sense of autonomy, identity and wellbeing which can support social and community participation. Positive changes in these areas can in turn promote and result in an improvement in mental health outcomes.

Personalisation/person-centredness comes from a citizen's rights based tradition with individual self-determination as an underlying principle. Personalisation has two aspects: services are shaped to fit the needs of each individual; and this individualised approach is underpinned by a fundamental change in the relationship between the citizen and the state, from being recipients of services to actively exercising the right to control their lives (Alakeso, 2010). Person-centred approaches place a person experiencing mental health issues at the helm, making choices, shaping the direction of supports and services and taking control of their life, however challenging this may be and however long it may take (Mental Health Commission 2013).

Although these two concepts have been shaped and influenced by two separate sectors the principles underpinning them overlap and manifest into practice by consumers self-directing the support they need to live a good life in their community.

The introduction of the [National Disability Insurance Scheme](#) (NDIS) and the new [National Disability Service Standards 2013](#) for people with disability further builds on this individual and person-centred approach with a focus on individual needs and choices. Under the NDIS, people with disability are able to make decisions about the support services they access to live their life and achieve their goals their way (NSW Government, 2014).

The strategic policy document, [Mental Health 2020: Making it personal and everybody's business](#) (Mental Health Commission, 2013) also recognises that people with disability have a greater likelihood of experiencing mental health problems and discrimination and would benefit from a person-centred and coordinated (collaborative) approach to effectively improve their mental health outcomes.

## 4.0 The workforce

People with intellectual disability and co-occurring mental health issues are likely to be in contact with a range of services due to their multiple needs. They may need help with housing, obtaining employment, or participating in social activities, and require access to multiple health related services. This group has also been identified as having a higher incidence of contact with the justice system.

Service responses are greatly improved where there is a workforce skilled across a range of disciplines as well as having appropriate systems and structures in place to improve access and equity for this consumer group, their carers, family members or guardians.

Given the difference in roles, education, training and experience of the service providers who would be involved in supporting a person with intellectual disability and co-occurring mental health issues, it is not expected that all staff will address all the capabilities to the same extent. For example, a Police Officer will come into contact with a person with intellectual disability and co-occurring mental health issues only occasionally, such as when called out to an incident, while a disability support worker may have daily interaction with a person over many years. Both workers will be required to respond appropriately within the context of the interaction and the details and complexity of this involvement will vary considerably.

It is hoped that the mental health, disability, general health and the wider human services sectors will adopt these core capabilities to recognise and support enhanced service provision to meet the specific needs of people with intellectual disability and co-occurring mental health issues by using this Framework to:

- Establish and reinforce underlying principles for good service design and practice;
- Identify the attributes, skills and knowledge required to improve professional Practice;
- Adapt a core set of capabilities that can be used to meet service standards; and
- Identify the legal requirements that ensure provision of inclusive and accessible services.

A collaborative and multidisciplinary approach between health, mental health and the disability sectors is required to support people with intellectual disability and co-occurring mental health issues. To achieve this, staff within support organisations require a minimum skill set across mental health and disability relevant to their roles. This will improve service delivery and increase confidence to manage presenting issues, rather than referring a person to another service based on their underlying issue.

## 5.0 The Capability Framework

### 5.1 About the Framework

This Framework provides a foundation for use at an individual and organisational level. They are not service standards, but rather enhance an organisation's capacity to achieve service standards by a) ensuring best practice techniques are used by competent staff, and b) governing policies and process are identified that reinforce the capabilities.

The framework can be viewed at an individual and organisational level.

**Individual** To develop, assess and monitor an individual's capabilities to work with the specific target group.

**Organisational** To improve quality systems and processes, ensure best practice in service delivery, and ensure compliance with relevant legislation and regulations.

The Framework comprises:

1. **Principles** - The guiding principles set out the core values that are important in guiding decisions and work in this area. (Refer to section 5.3)
2. **Domains** - Sets out five key areas of practice which a) align to and that are required to provide a holistic service model to support people with an intellectual disability and co-occurring mental health issue.
3. **Capabilities** - The capabilities are sets of knowledge, skills and attributes that relate to tasks, management, job roles and working environments. They are not service standards but rather enhance an organisation's capacity to achieve their service standards by ensuring best practice techniques are used by competent staff, and governing policies and process are identified that reinforce the capabilities. Embedding these capabilities requires a whole of organisation response and is an ongoing process that requires adoption at an organisational level, ensuring the proper processes and systems are in place to support individual capabilities.
4. **Skills, knowledge and attitudes (SKA)** - Under each set of capability sits the skills (behaviours), knowledge and attitudes (values) required to effectively perform a role or specific task, in this case as it relates to working with people with an intellectual disability and co-occurring mental health issue, and for the organisation to meet the capability set within each domain. These skills, knowledge and attitudes are cumulative in nature. That is, it is assumed that capabilities at lower levels are present at successively high levels in line with job role.
5. **Governing policies and processes** - This Framework has included governing policies and processes under each capability. This will support embedding these capabilities as a whole of organisation response ensuring the proper processes and systems are in place to support individual capabilities.

Together the guiding principles, capabilities, and skills, knowledge and attitudes and governing policies and processes can be used to assist in professional development planning.

### 5.2 Relationship to legislation and other standards/capability frameworks

The role of legislation, regulatory bodies and charters has been developed over time to promote and protect the rights of people with a disability. This is particularly important when it comes to obtaining consent for treatment decisions and access to services. Organisations' must have in place appropriate policies based on current legal and professional requirements. For example, many professions in the health, mental health, disability and human service sectors already adhere to human rights, occupational or sector-specific practice standards. Organisations' are required to ensure all staff are aware of and adhere to the following standards when advocating for or supporting a person with intellectual disability:

- [Carers Recognition Act 2004](#);
- [UN Convention on the Rights of Persons with Disabilities 2006](#);
- [Mental Health Act 2014](#); and
- [Guardianship and Administration Act 1990](#) (see [Office of the Public Advocate](#)).

This Framework assumes that organisations' already meet the minimum standards required to work in their field of expertise and that they adhere to the standards of basic human rights. It has been designed to complement these standards and to cover specific capabilities required to support access for people with intellectual disability and co-occurring mental health issues, and should be used in conjunction with these.

Relevant key documents include:

- [Accessible Mental Health Services for People with an Intellectual Disability: A Guide for Providers 2014](#);
- [National Mental Health Core Capabilities 2014](#);
- [A national framework for recovery-oriented mental health services 2013](#);
- [National Standards for Mental Health Services 2010](#);
- [Service Framework to improve the Health Care of People with Intellectual Disability 2012](#); and
- [Framework for Mental Health in Multicultural Australia: Towards culturally inclusive service delivery 2014](#).

## 5.3 Five guiding principles of the Framework

This Framework is underpinned by **five guiding principles**. These principles are designed to govern all practice, decisions and interactions in the provision of service delivery and practice when working with someone with intellectual disability and co-occurring mental health issues.

### **Principle 1: Rights**

People with intellectual disability, including those with a co-occurring mental health issue, and their families, carers and guardians have the right to have access to social, cultural and economic environments in relation to health and wellbeing as outlined in the UN Convention on the Rights of Persons with Disabilities. This includes rights to healthcare met by mainstream health services equal to that available to consumers who do not have intellectual disability and co-occurring mental health issues. With respect to consumers with decision making disabilities, processes should enable their rights to be explained to them in a manner in which they are likely to be understood.

### **Principle 2: Inclusion**

Required processes and structures are put in place to support access to services and the right to participate in community life by people with intellectual disability and co-occurring mental health issues. This extends to inclusion of their carers, family members or guardians.

### **Principle 3: Holistic approach**

People with intellectual disability and co-occurring mental health issues are part of a person-centred approach to ensure they are supported to make choices and are in control of their care. This involves a holistic approach drawing on a variety of health and community service professionals working collaboratively with the consumer, their carers, family members or guardians where appropriate.

### **Principle 4: Recovery oriented practice**

People with intellectual disability and co-occurring mental health issues are supported to take responsibility for their lives respecting their experiences, expertise and strengths. This may include the involvement of their carers and family members to ensure that consumers with intellectual disability and co-occurring mental health issues are supported and enabled to effectively implement any changes that support their recovery journey. Support should be inclusive, holistic, and collaborative to ensure ongoing quality of life and wellbeing.

### **Principle 5: Evidence-based and quality services**

Best possible outcomes are sought by keeping informed of best available evidence, regularly reviewing policy and practice against standards and current legislation, and participating in professional development.

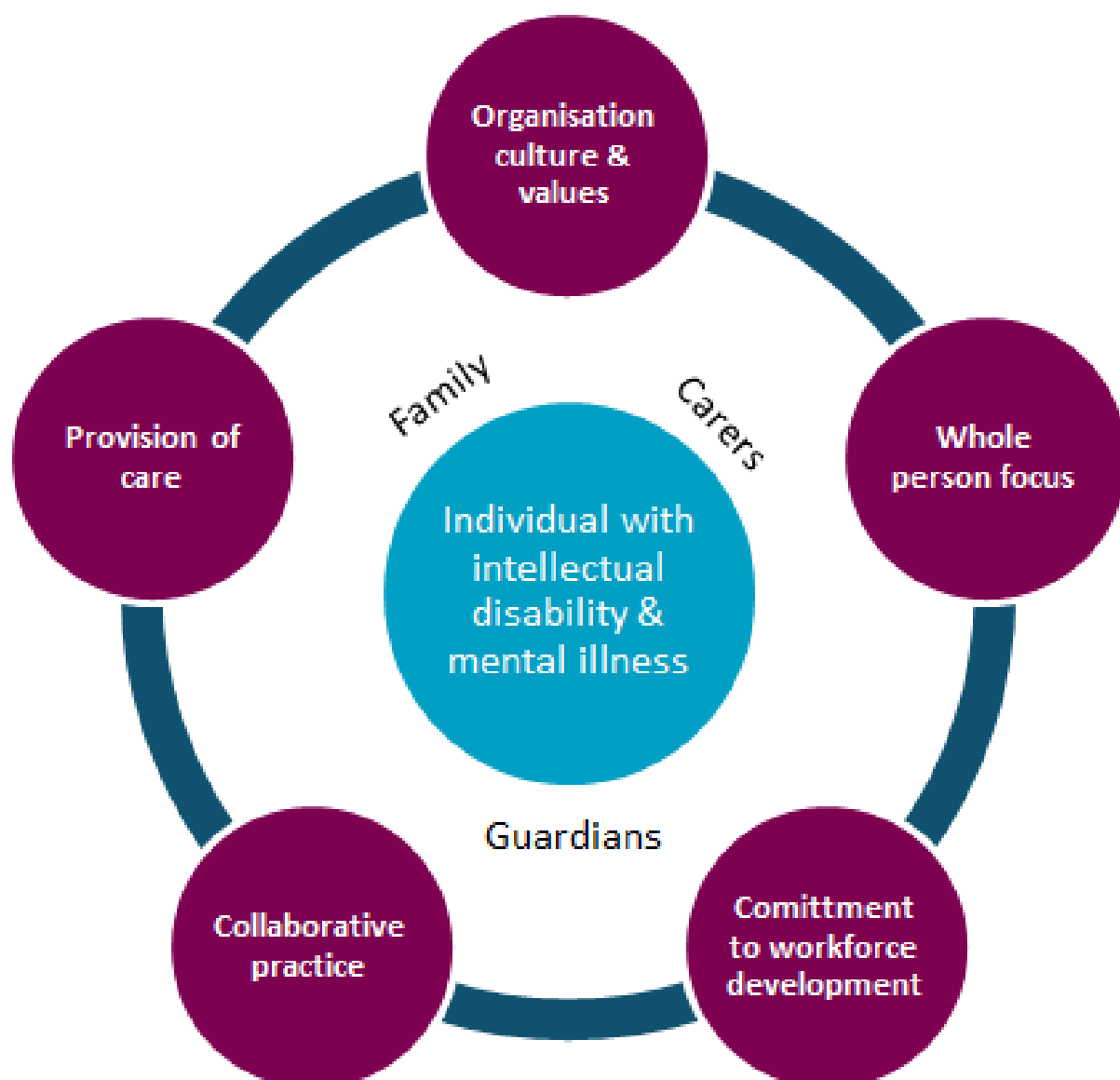


## 5.4 The five domains

The Framework has been designed to cover five key areas of practice referred to as **domains**:

1. Organisational culture and values;
2. Whole person focus;
3. Commitment to workforce development;
4. Collaborative practice; and
5. Provision of care.

The role of carers, family members or guardians for people with intellectual disability is important in assisting with maintaining wellbeing and supporting decision making. As such, they too are at the centre of the domains.



### 5.4.1 Organisational culture and values (domain 1)

Services are underpinned by a human rights framework which promotes and supports the inclusion of people with intellectual disability and co-occurring mental health issues and, where appropriate, their carers, family members or guardians. This includes ensuring appropriate systems and policies are in place to meet the core capabilities.

Best practice within this domain relies on two key capabilities:

**Capability 1A: Provides people with intellectual disability and co-occurring mental health issues, and their carers, family members or guardians with the same access, range and quality of services available to those without disability.**

**Capability 1B: Complies, and acts in accordance, with professional, ethical and legal standards.**

To achieve these capabilities organisations and individuals must demonstrate the following:

<b>Values and attitudes</b>	<ul style="list-style-type: none"> <li>- Respect and value a person’s individual rights to a high standard of health and full participation in personal and community life.</li> <li>- Services are provided in an ethical and legal manner.</li> </ul>
<b>Knowledge</b>	<ul style="list-style-type: none"> <li>- Relevant provisions of the <i>Disability Discrimination Act 2004</i>, <i>Carers Recognition Act 2004</i> and the Carers Charter, <i>Guardianship and Administration Act 1990</i> and other relevant legislation, regulations and standards.</li> <li>- Person-centred and consumer directed approaches.</li> <li>- Consumer rights including duty of care and privacy.</li> <li>- Awareness of consent and processes to support capacity to consent as required under the <i>Guardianship and Administration Act 1990</i>.</li> <li>- The role of the Public Advocate.</li> <li>- Equity and access issues for people with intellectual and co-occurring intellectual disability and mental health issues.</li> </ul>
<b>Core skills and behaviours</b>	<ul style="list-style-type: none"> <li>- Actively respects and upholds the rights of people with intellectual disability and co-occurring mental health issues, their carers, family members or guardians including taking instruction as required by guardianship orders.</li> <li>- Provides care, support and treatment to individuals and their carers, family members or guardians within the boundaries prescribed by law, professional standards, and codes of ethical practice.</li> <li>- Provides reasonable adjustments to accommodate the person and their individual needs.</li> <li>- Recognises when someone may not have the capacity to consent and follows necessary procedures.</li> <li>- Follows processes required to determine a person’s capacity to treatment decisions and when in doubt, apply to the State Administration Tribunal (SAT).</li> </ul>

**Governing policies and processes**

- Implements systems and processes to enable access to services and social supports for people with intellectual disability and co-occurring mental health issues.
- Identifies and addresses barriers to access and participation by people with intellectual disability and co-occurring mental health issues.
- Provides information on the rights of people with an intellectual disability, their carers, family members or guardians in accessible formats.
- Ensures policies, procedures and processes are kept up-to-date and comply with legislative, service standards and legal requirements.

**5.4.2 Wholeperson focus (domain 2)**

Services are designed to reflect the requirements and needs of the individual with intellectual disability and co-occurring mental health issues, and where appropriate their carer, family members or guardian.

Best practice within this domain relies on three key capabilities:

**Capability 2A:      Respect and understand individual differences and diversity that takes into account a person’s age (actual and developmental), capacity and cultural beliefs.**

**Capability 2B:      Promote independence and empower people with intellectual disability and co-occurring mental health issues.**

**Capability 2C:      The roles of carers, family members and guardians are acknowledged and valued.**

To achieve these capabilities, organisations and individuals must demonstrate the following:

<b>Values and attitudes</b>	<ul style="list-style-type: none"> <li>- Diversity is embraced and accommodated.</li> <li>- All individuals have the right to make decisions about their health care.</li> <li>- The role of the carer is respected and acknowledged.</li> </ul>
<b>Knowledge</b>	<ul style="list-style-type: none"> <li>- Adaptive communication techniques and accessible formats.</li> <li>- Different cultural perceptions of disability and mental health.</li> <li>- Recovery and person-centred approaches.</li> <li>- Social determinants of mental wellbeing.</li> <li>- Local, support and specialist services available.</li> <li>- Role of carers, family members or guardians in the provision of care.</li> </ul>
<b>Core skills and behaviours</b>	<ul style="list-style-type: none"> <li>- Able to make referrals to support networks with consideration to a person’s age (developmental and actual), gender and cultural origin where possible.</li> <li>- Identifies communication needs and adapts own communication style to suit situation including the use of adaptive technologies.</li> <li>- Skilled in and adapts work practices to reflect the age, ethnicity and</li> </ul>

	<p>developmental capacity of the individual.</p> <ul style="list-style-type: none"> <li>- Provides information in accessible formats.</li> <li>- Works with carers, family members or guardians acting on behalf of a person with intellectual disability.</li> <li>- Actively supports and empowers people with intellectual disability and co-occurring mental health issues to exercise their rights and make decisions about their mental health, wellbeing and life, which may require the involvement of carers, family members and/or guardians.</li> <li>- Involves the individual's carers, family members or guardians as an important component in prevention, early intervention, treatment and recovery.</li> <li>- Identifies stressors/triggers and ways to support the recovery journey.</li> </ul>
<b>Advanced skills and behaviours</b>	<ul style="list-style-type: none"> <li>- Regularly re-visits the consent to healthcare of the person with intellectual disability and co-occurring mental illness/health issue to allow for changes in their capacity.</li> <li>- Skilled in advanced alternative models of information collection that reflect the communication barriers faced by people with intellectual disability and co-occurring mental illness.</li> </ul>
<b>Governing policies and processes</b>	<ul style="list-style-type: none"> <li>- Actively engage in and supports collaborative practices across service providers.</li> <li>- Staff have access and are trained in relevant service standards, legislation, regulations and policies.</li> <li>- Ensure policies, procedures and processes are kept up-to-date and comply with service standards and legal requirements.</li> </ul>

### 5.4.3 Commitment to workforce development (domain 3)

Services and work environments are committed to building a workforce that is appropriately skilled, equipped, supported and resourced to support people with intellectual disability and co-occurring mental health issues, and their carers, family members or guardians.

Best practice within this domain relies on two key capabilities:

**Capability 3A:** Workforce planning takes into account the training and skills required to work with people with intellectual disability and co-occurring mental health issues, and their carers, family members or guardians.

**Capability 3B:** Establish and maintain systems, procedures and processes that support continuous improvement in working with someone with intellectual disability and co-occurring mental health issues, and where appropriate their carer, family member or guardian.

To achieve these capabilities, organisations and individuals must demonstrate the following:

<b>Values and attitudes</b>	<ul style="list-style-type: none"> <li>- Commitment to learning, and developing staff skills.</li> <li>- Values, philosophies, and standards that apply to working with people with intellectual disability and co-occurring mental health issues.</li> </ul>
<b>Knowledge</b>	<ul style="list-style-type: none"> <li>- Awareness of <i>Disability Discrimination Act 2004</i>, <i>Carers Recognition Act 2004</i> and its Charter and other relevant legislation, regulations and policies.</li> <li>- Tools, resources and training relevant to working with people with an intellectual disability and co-occurring mental illness.</li> <li>- Social model of disability and recovery model.</li> <li>- Range of services available across sectors commonly accessed by people with an intellectual disability and co-occurring mental illness and their carers, family members or guardian.</li> <li>- Government benefits in disability, housing and accommodation.</li> <li>- Values, philosophies, and standards that apply to working with people with an intellectual disability and co-occurring mental illness.</li> </ul>
<b>Core skills and behaviours</b>	<ul style="list-style-type: none"> <li>- Tools, resources and training relevant to working with people with intellectual disability and co-occurring mental health issues, including different cultural perspectives.</li> <li>- Identify own and other staff training needs consistent with job role.</li> <li>- Identify and participate in training on communication tools for working with people with intellectual disability and co-occurring mental health issues.</li> <li>- Participate in workforce development and professional development opportunities that will improve personal and organisational service to the consumer group.</li> <li>- Uphold values, philosophies and standards for working with people with intellectual disability and co-occurring mental health issues, and their carer's, family members or guardians.</li> <li>- Follow organisational systems, procedures and processes.</li> <li>- Actively work with consumer, peer, carer and family groups to support care and advance their knowledge of services and treatment options.</li> </ul>
<b>Advanced skills and behaviours</b>	<ul style="list-style-type: none"> <li>- Undertake advanced training in adaptive communication techniques and assistive technology to assess the needs and support requirements of someone with intellectual disability and co-occurring mental health issues.</li> </ul>
<b>Governing policies and processes</b>	<ul style="list-style-type: none"> <li>- Identify professional development needs of staff.</li> <li>- Continually seek out information and resources to improve staff skills in supporting people with intellectual disability and co-occurring mental health issues.</li> <li>- Promote the development and regular review of procedures and processes to improve service delivery to people with intellectual disability and co-occurring mental health issues.</li> <li>- Include appropriate levels of awareness of intellectual disability and</li> </ul>

	<p>co-occurring mental health issues in induction programs.</p> <ul style="list-style-type: none"> <li>- Ensure the mission, values, policies and procedures reflect standards and legislative requirements for working with people with intellectual disability and co-occurring mental health issues, and their carer’s, family members or guardians.</li> </ul>
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#### 5.4.5 Collaborative practice (domain 4)

Services are committed to maintaining effective working relationships, and work in partnership with others to support people with intellectual disability and co-occurring mental health issues and their carers, family members or guardians.

Best practice within this domain relies on two key capabilities:

**Capability 4A: Establish networks with relevant service providers, senior staff or experts to support a whole-of-person approach to care for someone with intellectual disability and co-occurring mental health issues, and their carer, family member or guardian.**

**Capability 4B: Provide objective, linguistically appropriate, accurate and detailed health and mental health information to services and people involved in the on-going support of people with intellectual disability and co-occurring mental health issues.**

To achieve these capabilities, organisations and individuals must demonstrate the following:

<b>Values and attitudes</b>	<ul style="list-style-type: none"> <li>- Openness to draw on the expertise of others.</li> <li>- Consumers’ interests are paramount.</li> </ul>
<b>Knowledge</b>	<ul style="list-style-type: none"> <li>- Referral, support and transition care pathways for people with intellectual disability and co-occurring mental health issues.</li> <li>- Current best practice guidelines in supporting someone with intellectual disability and co-occurring mental health issues, and their carer, family member or guardian.</li> <li>- Recognition of the social model of disability and the subsequent impact of disability on mental health.</li> <li>- Access to assess the social factors influencing an individual’s life to help identify areas that may need addressing or strengthening.</li> <li>- Methods of conducting comprehensive individual support plans and discharge plans, if appropriate.</li> <li>- Cross-sectoral care and treatment options.</li> <li>- Processes and systems to ensure continuity of care and active involvement of carers, family members or guardians as required.</li> </ul>
<b>Core skills and behaviours</b>	<ul style="list-style-type: none"> <li>- Develop cross-sectoral service collaboration and partnerships in care with service providers and carers, where appropriate, to deliver the best possible health and mental health outcomes.</li> <li>- Collaborate with other health professionals to establish goals that are clear and measurable, and demonstrate shared ownership.</li> <li>- Contribute to and participate in handover and transfer processes as</li> </ul>

	<p>appropriate.</p> <ul style="list-style-type: none"> <li>- Maintain comprehensive documentation as required by the role.</li> <li>- Conduct needs assessments to identify the supports required by people with intellectual disability and co-occurring mental health issues, as appropriate to the role.</li> </ul>
<b>Advanced skills and behaviours</b>	<ul style="list-style-type: none"> <li>- Develop skills in managing therapeutic cooperation and coordinated care with other relevant staff and organisations.</li> <li>- Conduct comprehensive individual support and discharge plans, if appropriate.</li> <li>- Ensure the person's needs and wishes are communicated in the handover or transfer of care.</li> </ul>
<b>Governing policies and processes</b>	<ul style="list-style-type: none"> <li>- Design services to enable collaborative practice amongst professionals from different disciplinary backgrounds.</li> <li>- Establish systems to ease consumer transitions between services.</li> <li>- Processes and systems are continually reviewed to ensure good quality service.</li> </ul>

#### 5.4.5 Provision of care (domain 5)

Services participate in the planning, delivery and management of evidence-based, recovery-focused treatment. This includes the care and support for people with intellectual disability and co-occurring mental health issues, including services for their carers, family members or guardians where required.

Best practice within this domain relies on two key capabilities:

**Capability 5A: Recognise a person with intellectual disability can also have mental health issues and will require adjustments in the provision of support.**

**Capability 5B: Manage and effectively use recovery principles and processes to improve the social, physical, psychological and mental health of someone with intellectual disability and co-occurring mental health issues.**

To achieve these capabilities, organisations and individuals must demonstrate the following:

<b>Values and attitudes</b>	<ul style="list-style-type: none"> <li>- Provide a person-centred holistic approach: social, physical, emotional and spiritual and cultural needs of the individual.</li> </ul>
<b>Knowledge</b>	<ul style="list-style-type: none"> <li>- Importance of conducting biographical history, current/recent stressors, triggers.</li> <li>- Person-centred and recovery-oriented practice.</li> <li>- Risk and behavioural management tools and techniques.</li> <li>- Assessment tools used in diagnosis and communicating with someone with intellectual disability and co-occurring mental health issues, relevant to job role.</li> <li>- Clinical symptomatology of people with intellectual disability and co-occurring mental health issues.</li> </ul>



	<ul style="list-style-type: none"> <li>- Common co-morbidities experienced by someone with intellectual disability.</li> <li>- Methods of conducting comprehensive individual support plans.</li> </ul>
<b>Core skills and behaviours</b>	<ul style="list-style-type: none"> <li>- Recognise that mental health issues may present as a behavioural disorder or ‘challenging behaviours’ when there is co-occurring intellectual disability.</li> <li>- Identify signs of mental health issues in a person with intellectual disability, and signs of intellectual disability in a person presenting with mental health issues.</li> <li>- Make necessary adjustments including: allocation of adequate time; physical environment; establishing communication needs; accommodating carers, family members or guardians where required.</li> <li>- Collaborate across health, community and social service organisations to develop individualised plans reflecting current and long-term needs and goals for people with intellectual disability and co-occurring mental health issues.</li> <li>- Undertake ‘active referral’.</li> <li>- Identify and manage risks including violence, aggression and harm to self or others.</li> </ul>
<b>Advanced skills and behaviours</b>	<ul style="list-style-type: none"> <li>- Perform a comprehensive history noting features for diagnosis from the individual and their carers, family members or guardians.</li> <li>- Actively engage people with intellectual disability or mental health issues, and their carers, family members or guardians as potential co-investigators in the diagnostic and management process.</li> <li>- Employ a multi-disciplinary approach to problem-solving best support options.</li> <li>- Conduct a comprehensive assessment of needs using the appropriate diagnostic tools.</li> </ul>
<b>Governing policies and processes</b>	<ul style="list-style-type: none"> <li>- Resources are allocated to meet individualised needs and support.</li> <li>- Staff have access to current assessment tools and resources.</li> </ul>

## 6.0 Glossary

### **Adaptive Functioning**

Refers to someone's ability to function and handle the normal demands of life such as caring for one's self (life skills). Adaptive functioning is affected by three basic skill sets:

- practical skills — feeding, bathing, working, transport
- social skills — obeying the law, understanding social rules and customs
- conceptual skills — reading, maths, understanding money

### **Adaptive or assistive technologies**

Refers to using hardware, software or developed tools and resources to assist with a task. For example, adaptive technologies in communicating with someone with intellectual disability may require the use of Key Word Signs rather than just verbal communication.

### **Acquired Brain Injury**

Refers to damage occurring to the brain after birth which can result in some cognitive or learning difficulties. This can occur as a result of an accident, stroke, brain infection, drugs and alcohol misuse or disease. This may result in psychological disturbances (Better Health Channel, no date cited).

### **Active referral**

Active referral is a term used to describe a process of referral to other external services where the staff member takes an active role in that referral; for example telephones the other agency with the consumer present and with their consent to make appointments and provides information about the consumer assessment/needs (Mills, 2008).

### **Allied Health Worker**

An allied health worker is a tertiary-trained practitioner who works with others in the health-care team to support a person's medical or mental health care. Examples include psychologists, physiotherapists, occupational therapists, speech pathologists, podiatrists, dieticians, and social workers. The term 'allied health' does not apply to medical health professionals such as doctors, surgeons, nurses, psychiatrists or dentists (Better Health Channel, no date cited).

### **Autism spectrum disorder**

A lifelong developmental disability characterised by marked difficulties in social interaction, impaired communication, restricted and repetitive interests and behaviours, and sensory sensitivities. Autism Spectrum Disorder includes autistic disorder (or 'classic' autism); Asperger's disorder; and pervasive developmental disorder not otherwise specified (PDD-NOS), also known as atypical autism. People with Autism Spectrum Disorder have intellectual disability if they meet the criteria for intellectual development disorder in the DSM-V assessment scale.

### **Biopsychosocial**

Refers to the concept that biological, social and psychological factors all play a part in health and wellness.

### **Carer**

The *Carers Recognition Act 2004* describes a carer as someone who “...provides ongoing support, care or assistance to a person with disability or a chronic illness (which includes mental illness) or who is frail”. This term does not include those people referred to as Carers who are in a paid position: see Support Worker.

### **Challenging behaviour**

Culturally abnormal behaviour of such an intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour which is likely to seriously limit use of, or result in the person being denied access to, ordinary community facilities (Emerson, 1995). These behaviours can present as aggression, withdrawal, inappropriate behaviours or behaviour that leads to self-harm.

Challenging behaviours can be related to physical, psychiatric or social influences e.g.: unrecognised pain, moving house, family problems, communication issues, avoiding demands, depression (Centre for Developmental Disability Health Victoria, not cited).

### **Cognitive impairments**

A cognitive impairment refers to problems in processing in the brain in one or more of the following areas: memory, communication, attention, thinking and judgement. This may be present at birth or may occur later in life e.g.: dementia, specific learning disabilities, attention deficit disorder (Australian Commission on Safety and Quality in Health Care, 2013).

### **Co-morbidity/co-morbidities**

This refers to the existence of more than one health related issue commonly experienced by people with intellectual disability, including medical conditions and mental health issues. For example, people with William’s Syndrome are more likely to have hypertension, diabetes and anxiety than the general population; people with Prader Willi Syndrome have high rates of obesity, osteoporosis, OCD, anxiety and depression (Durban Region Dual Diagnosis Committee, 2010).

### **Diversity**

A broad concept that includes age, cultural heritage, education, functional capacity, gender, and social status.

### **Diagnostic overshadowing**

The process of over-attributing symptoms displayed to one particular condition which, in turn, results in comorbid conditions being undiagnosed and untreated. The term was originally used in relation to people with developmental disabilities, where their psychiatric symptoms were falsely attributed to their disability, leaving their mental health issues undiagnosed (Vahabzadeh, 2013).

### **Guardian**

A 'guardian' is a substitute decision-maker with an authority to make personal, lifestyle and treatment decisions about the person under guardianship. The *Guardianship and Administration Act 1990* provides for the appointment of guardians to safeguard the best interests of adults with decision-making disabilities. A guardian is appointed for a specific period of time and is given specific functions. A private guardian (e.g.: family or friend) may be appointed provided the circumstances allow for this (Office of the Public Advocate, 2013).

### **Individual support plan**

In this document, an individual support plan includes plans that may also be referred to as 'care plans' in the medical field and 'support plans' in the disability field. It refers to a process of documenting the agreed care and support arrangement of a person with intellectual disability and co-occurring mental health issue.

### **Intellectual disability**

Also known as "Intellectual developmental disorder" refers to the existence of developmental deficit fulfilling the conditions below:

- a) Significant sub-average intellectual functioning, i.e., an Intelligence Quotient (IQ) score of 70 or below;
- b) Concurrent deficits or impairments in adaptive functioning;
- c) Onset before age 18 years.

To avoid any confusion people with Autism Spectrum Disorders who meet the criteria for intellectual development disorder in the DSM-V assessment scale fall within this target group.

### **Intellectual disability and co-occurring mental health issues**

Coexistence of intellectual disability with concurrent psychiatric disorders (mental illness, mental health problems).

### **Mental health issue**

Disruption of normal function caused by disturbances of mood or thought that adversely affect the individual, their behaviour and those around them. This includes people who do not meet the diagnostic criteria for DSM-V. The term can be used to describe suspected or undiagnosed mental illness.

### **Mental illness**

Refers to 'disturbances in mood or thought that can affect behaviour and distress the person or those around them, so the person has trouble functioning normally' (National Mental Health Commission, 2012). This includes diagnosed conditions as defined by DSM-V.

### **Recovery model of practice**

At the core of this approach is supporting a person living with a mental health issue to develop life skills and abilities, and learn ways to recover that builds their confidence, self-esteem and resilience for the future. Recovery is not about living a life symptom free but facilitating opportunities and creating environments that support an individual reclaim their identity outside of the mental health issues. Professionals (mental health workers) assist with the treatment and support by adding their expert knowledge and skills in a holistic way and act as partners in

recovery (State of Victoria, Department of Health, 2011). Recovery is underpinned by four principles or processes: Finding and maintaining hope; Re-establishing a positive identity; Building a meaningful life; Taking responsibility and control (Commonwealth of Australia, 2013).

### **Support Worker**

A worker is a qualified person working in the social welfare or community sector program intended to promote or restore the social functioning of individuals, families, social groups or the larger community (Australian Community Workers Association, no date cited). Roles include Outreach Worker, Rehabilitation Counsellor, Disability Support Worker, Youth Worker, Financial Counsellor, Housing Officer.

### **Treatment**

Any medical, surgical or dental treatment or other health care, including life sustaining measures and palliative care (*Guardian Administration Act 1990*).

## 7.0 Appendices

### 7.1 Appendix 1: Training and education resources

#### **Mental Health Commission WA**

As part of this project, a two day training package will be developed to cover the core competencies required to work with people with intellectual disability and a co-occurring mental health issue or mental health problem.

For further information see: [www.mentalhealth.wa.gov.au](http://www.mentalhealth.wa.gov.au)

#### **Royal Australian and New Zealand College of Psychiatrists**

The Royal Australian and New Zealand College of Psychiatrists have developed a range of e-learning resources for the use of its members and other mental health professionals. Including prescribing psychotropic medication for people with an intellectual disability and co-occurring mental health issues.

For further information see: <https://www.ranzcp.org/Publications/E-learning.aspx>

#### **Blooming Minds**

Blooming Minds is a private training organisation specialising in Mental Health. They have developed training on Mental Health First Aid for the Disability Sector.

For further information see: [www.bloomingminds.com.au](http://www.bloomingminds.com.au)

#### **Centre for Developmental Disability Health Victoria**

Centre for Developmental Disability Health Victoria (CDDHV) is working with the Royal Australian College of General Practitioners to develop online educational activities on the health and healthcare of people with a developmental disability. CDDHV also offers undergraduate and postgraduate courses and training programs with opportunities to participate in teaching and research. The Centre has produced an interactive learning resource for health professionals.

For further information see: [www.cddh.monash.org](http://www.cddh.monash.org)

#### **Information on Disability Employment Western Australia**

Information on Disability Employment Western Australia (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.

For further information see: [www.ideaswa.net/training-manuals.html](http://www.ideaswa.net/training-manuals.html)

## **Intellectual Disability Mental Health e-Learning**

This e-Learning website has been developed by the Department of Developmental Disability Neuropsychiatry as a free training resource to improve mental health outcomes for people with 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 supporting people with intellectual disability and co-occurring mental health issues.

For further information see: [www.idhealtheducation.edu.au](http://www.idhealtheducation.edu.au)

## **Mental Health Professional Online Development**

Mental Health Professional Online Development (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 one topic with a focus on intellectual disability and co-occurring mental health issues and other developmental disability and mental health issues.

For further information see: [www.mhpod.gov.au](http://www.mhpod.gov.au)

## **The Queensland Centre for Intellectual and Developmental Disability**

The Queensland Centre for Intellectual and Developmental Disability (QCIDD) provides undergraduate and postgraduate education for the health professionals. QCIDD provides collaboration innovation around teaching through the Student doctors as Health Advocates Program where second year medical students have an opportunity to spend time with a person with intellectual disability and to attend their annual health check with the general practitioner. QCIDD also provides education to the community and disability sectors in the form of workshops, courses and conferences.

For further information see: [www.som.uq.edu.au/research/research-centres/queensland-centre-for-intellectual-and-developmental-disability.aspx](http://www.som.uq.edu.au/research/research-centres/queensland-centre-for-intellectual-and-developmental-disability.aspx)

## **Victorian Dual Disability Service**

Victorian Dual Disability Service (VDDS) is a mental health service for people with intellectual disability and co-occurring mental health issues. 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.

For further information see: [www.svhm.org.au/services/VictorianDualDisabilityService](http://www.svhm.org.au/services/VictorianDualDisabilityService)



## 7.2 Appendix 2: Communication tolls and links to other documents

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

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

For further information see:

[http://ddi.wayne.edu/pdf/assessing\\_mental\\_health\\_concerns\\_inadults\\_with\\_id.pdf](http://ddi.wayne.edu/pdf/assessing_mental_health_concerns_inadults_with_id.pdf)

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

This publication provides guidelines for practitioners providing counselling services to consumers with complex communication needs associated with disability.

For further information see:

[www.scopevic.org.au/index.php/cms/frontend/resource/id/128](http://www.scopevic.org.au/index.php/cms/frontend/resource/id/128)

### Easy English Writing Style Guide

This booklet provides a range of guidelines to support the presentation of ‘easy-to-read’ information in accessible reports, brochures and flyers.

For further information see:

[www.scopevic.org.au/index.php/cms/frontend/resource/id/1663/name/EE%20Style%20Guide\\_2013\\_web.pdf](http://www.scopevic.org.au/index.php/cms/frontend/resource/id/1663/name/EE%20Style%20Guide_2013_web.pdf)

### Key Word Sign

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

For further information see: <http://www.newcastle.edu.au/research-andinnovation/centre/cseds/programs/key-word-sign-australia/implementing-key-word-signing>

**Guides to communicating with people with a learning disability or people with profound and multiple learning disabilities:**

Produced by Mencap in the United Kingdom, these guides are designed to provide an introduction to communication, and the problems faced by someone with a learning disability /intellectual disability. These guides contain information on how to be a better communicator, and how to assist someone with a learning disability/intellectual disability to communicate their message across.

For further information see the following links:

[www.mencap.org.uk/sites/default/files/documents/Communicating%20with%20people\\_updated.pdf](http://www.mencap.org.uk/sites/default/files/documents/Communicating%20with%20people_updated.pdf)

[www.plymouthhospitals.nhs.uk/ourservices/clinicaldepartments/learningdisability/Documents/communicatingwithpeoplewithPMLD\\_a%20guide.pdf](http://www.plymouthhospitals.nhs.uk/ourservices/clinicaldepartments/learningdisability/Documents/communicatingwithpeoplewithPMLD_a%20guide.pdf)



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