

CDDH FACT SHEET

Working with people with intellectual disabilities in healthcare settings

People with intellectual disabilities have the same right as other community members to access community based health services.

The definition of intellectual disability requires that an individual has an IQ below 70 along with significant difficulties in adaptive behaviours and daily living skills such as self-care, communication and community participation.

2-3% of the population have an intellectual disability – that's around 100,000 Victorians - although only a proportion seek and receive disability specific services. All healthcare professionals will see people with an intellectual disability in their practice and therefore need a basic understanding of key concepts in order to provide high quality care.

Implications of intellectual disability

People with intellectual disability:

- Learn and process information more slowly.
- Have difficulty with abstract concepts such as money, time and the subtleties of interpersonal interactions.

The kind of support and assistance they require depends on:

- Their cognitive ability.
- Expectations on them within particular environments.
- Whether they have other associated developmental disabilities such as cerebral palsy, autism or sensory impairments.

Each one of us is unique. Our IQ provides a guide as to how quickly we are able to process new information, grasp abstract concepts and manipulate ideas. It reflects a part of our ability profile, but does not reflect our personality, our emotional or musical intelligence, our artistic ability, our interests and many other facets of who we are and how we engage with our world.

Each of us has areas of ability and other areas of function that we find difficult. Arbitrary categories of mild, moderate, severe and profound levels of intellectual disability, defined on the basis of IQ 'scores', provide a guide to the level and type of support an individual may need, but the way that person functions in his/her life will also depend on many other factors. Individual factors include personality, social and communication abilities, coping strategies and the presence of other disabilities (motor, social or sensory). The supports provided by family, friends and support staff are also crucial aspects of people's lives and have a profound influence on their confidence and function. Issues of access (including physical, social, communication, cognitive, financial access) to community based facilities and services also play a powerful role in either enabling or inhibiting opportunities for inclusion, participation and contribution and the ability of the individual to fulfil their community roles.

Someone with a mild intellectual disability (IQ 50-70) may learn to read and write (depending on educational opportunities). Most people have important relationships in their lives and participate in a range of activities and contribute to their families and their communities. Some people live and travel independently while others require support and assistance in using public transport, handling money, and planning and organising their lives. Most people can work, and some have a job, with or without a level of personal or employment support. Many people will form intimate relationships and some will marry and raise children with various levels of support from family, friends and the service system. People with mild intellectual disability will have trouble with academic learning and so reading, writing and numeracy may remain at a basic level. Some people have not learnt to read or write; many are self conscious about this and sensitivity is required when requesting people read information or complete written forms. Many people find the subtleties of interpersonal relationships and social rules difficult to understand (particularly as adolescents) and may inadvertently transgress social boundaries.

Someone with a moderate intellectual disability (IQ 35 – 50) will have important relationships in his/her life and will usually enjoy a range of activities with families, friends and paid support workers and form valued and lasting friendships. With specific travel training many people learn to use public transport on familiar routes, but may have difficulty handling money and problem solving when unexpected events occur. Most people can learn to recognise some words in context (such as Ladies/Gents/Exit). People with adequate vision will benefit from visual prompts to clarify meaning, such as daily timetables and pictures used in communication systems. People with a moderate intellectual disability will need lifelong support in managing finances, and planning and organising their lives and activities. Their ability to be independent in personal care tasks, such as toilet hygiene, dressing and bathing, will depend on opportunities to learn and practice these tasks, their level of cognitive ability, and the presence or absence of other developmental disabilities such as cerebral palsy.

Someone with a severe (IQ 20 – 35) **or profound** (IQ <20) **intellectual disability** usually recognises familiar people and has strong relationships with key people in their lives. Most will have little or no speech and will rely on facial expression and body language and gestures to express their needs or feelings and those interacting with and supporting them must be active and keen observers in interpreting changes in a person's demeanour or behaviour. Communication systems for people with this level of disability generally rely on photographs or objects to facilitate understanding, e.g. a picture of a cup, or the cup itself, may be used in conjunction with the spoken question, "*Would you like a drink?*". People with severe/profound disabilities will require lifelong assistance in personal care tasks, communication and support in accessing community facilities/services.

Note: The more severe the disability, the more likely it is that the person will have associated sensory impairments which further undermines their ability to engage and learn. Vigilance with respect to detection and attention to sensory impairment is therefore imperative.

Barriers to good health care

People with an intellectual disability encounter a number of specific barriers to good health care.

Examples include:

- Limited **literacy** may mean they miss out on health information in magazines, books and public health campaigns.
- Cognitive difficulties may lead to **difficulties understanding** the importance and long term implications of healthy diet, lifestyle choices, and disease screening.
- **Social/financial** circumstances may lead to difficulty implementing strategies to achieve and maintain a healthy diet, exercise regime and health monitoring.
- **Communication difficulties** between patient and health professionals may lead to inaccuracies in the understanding or reporting of concerns, symptoms and history.
- Communication, cognitive and economic issues in relation to **transport** may cause difficulty in accessing health services and/or following through on management recommendations.
- **Carer issues**. Carers may not know, or be able to provide, an accurate history of the person's symptoms or previous medical care. They may misinterpret or have difficulty implementing management strategies suggested by health professionals.
- **Health professional issues**. Health professionals may feel uncertain about managing the complexity of issues, and may not know where to get the support and information they need. They may rely on carers to arrange regular health checks and reviews.

Strategies for providing good healthcare

1. Attitude

Convey **respect** for the person with the disability through your verbal and non-verbal language.

Address the person **directly** and use an **appropriate tone of voice** consistent with their age— i.e. speak to an adult as another adult, not as a child, and don't raise your voice (unless the person has a hearing impairment!).

2. Communication

People with intellectual disabilities are likely to have some degree of receptive communication difficulty (i.e. have difficulty understanding). Some people may also have an expressive language difficulty (i.e. difficulty being understood)

Whatever their ability to understand or express themselves, people have a right to the same **courtesy** any other person can expect. Some people who have communication difficulties may bring a family member, support worker or advocate to the appointment, but the person themselves should always feel that they are the primary focus of the consultation.

Receptive communication:

People with an intellectual disability may have difficulty understanding language that is complex and contains abstract concepts or technical jargon. It is therefore important when talking with someone with an intellectual disability to:

- Speak **slowly** and leave pauses for the person to process your words.
- Speak **directly** to the person concerned; they are central place in the communication.

- Speak in **clear, short sentences** and **use simple words**. Pause to enable the person to process what you are saying. Avoid long, complex sentences, technical words or jargon.
- Ask **one question at a time** and provide adequate **time** for the person to process the question and then formulate and communicate their response.
- If the person uses a **communication device**, ensure they have access to it, read the directions (usually on or in the device/book) and use it with them.
- If it is necessary to obtain part/all of the **history from the carer** maintain the focus on the person with the disability through your eye contact, body language and/or touch.

Expressive communication:

People with an intellectual disability may have trouble expressing their concerns, symptoms, thoughts or feelings as their cognitive impairment makes identifying, understanding and verbalising these difficult. Some people may also have a coexisting physical condition that impacts on their speech. It is therefore important to keep the following points in mind:

- **Provide plenty of time** for the person to respond and formulate their questions
- **Ask them to show you** how they say “**yes**” and “**no**” (if it is unclear) – and then ask “yes/no” questions to clarify what they are saying.
- **Ask if they have a communication aid** (electronic device, book, board) that could help you understand – if so, ask if you could use it together to help you better understand.
- **Use visual cues** – objects, pictures or diagrams to clarify meaning. Observe facial expression and body language for further clues
- **Ask questions** to clarify what they are concerned about or are asking.

When you can't understand.

There will be times when you do not understand what the person is saying. In this situation it may be helpful to ask the person:

- To **repeat** what they have just said
- To say it in **another way** (using different words or with visual cues e.g. drawing)
- If you could ask an **accompanying support worker/family member** to help you understand;

If you still can't understand, show respect for the person and acknowledge the importance of their message and apologise for failing to understand. **Never pretend to understand!** To do this devalues the communication and is extremely disrespectful to the person concerned.

Working with someone who is not able to communicate intentionally

- Some people with severe or profound intellectual disability **may not be able to understand words** and may not be able to conceptualise a communication message, that is, they may not be able to **communicate intentionally**. Whether or not someone can communicate intentionally they are entitled to the same respect and care.
- They will, however, like everyone else, communicate their experience of internal or external stimuli through changes in their facial expression, body language and behaviour and will rely on others to observe and interpret these changes. It may be clear that a person finds a particular sensation unpleasant from their grimace and withdrawal; or that they are cold when they shiver and goose bumps appear on their arm.
- Although the history will be given by an accompanying family member or support worker the person themselves should always hold the central place within the consultation and be included in the discussion through the use of eye contact, body language and touch.

3. Working with carers

- Many people who have a disability will require the **support** of others (family members, friends or paid support workers) to access and participate in the consultation and follow through on the management recommendations.
- **Family members** usually have an extensive knowledge of the person's history, personality and function and are a valuable source of information.
- People living in staffed accommodation are supported by a **Disability Support Workers** who have training in working with people with a disability, but usually do not have any health training. Staff work in shifts and staff turnover can be high in some houses. Usually the staff member accompanying someone to a medical appointment knows them well, but sometimes this is not the case. This should be clarified in the consultation. Staff will usually have a Health File with them containing the person's health history. If more information is required ring the House Supervisor.
- **Healthcare professionals** need to respect the contribution carers make to the consultation through their areas of expertise, but not assume medical knowledge.
- **Management recommendations** should be carefully discussed and stated and written down clearly to ensure accurate communication with all those involved.
- **Regular review** should be arranged to monitor whether management recommendations are achieving anticipated outcomes and to detect adverse effects.

4. Knowledge and skills

The starting point when providing healthcare for someone with a disability is **“how would I manage someone of this age and gender who presented with this issue?”** Modifications of management may be required, but should be justified.

People who are not able to speak will **demonstrate their symptoms through their behaviour**. For instance they may refuse food if nauseated, refuse to walk if they have a painful foot, not respond if they have a hearing impairment.

Information about the health implications of particular disabilities is available on many reputable websites as diverse as the Better Health Channel, Down Syndrome NSW, Understanding Intellectual Disability and Health (www.intellectualdisability.info) and OMIM (www.omim.org)

5. Health promotion and disease prevention

- Health promotion and disease prevention may be overlooked in people with disabilities because more urgent acute issues take priority.
- It is important to **schedule consultation times** (at a separate appointment if necessary) to address health promotion issues such as drug/alcohol use, healthy diet, exercise regime and screening tests. Indications are the same as people of a similar age in the general population.
- **Annual Health Assessments** (e.g. using the CHAP (Comprehensive Health Assessment Program)) are funded under Medicare to provide an annual thorough health assessment for people with intellectual disability. These assessments provide an ideal opportunity to ensure disease prevention and health promotion activities are addressed.

Summary of communication tips that may help when talking with someone with a disability

1. **Ensure you have the person's attention**
Address the person by name, use eye contact and/or touch.
2. **Be aware of known communication difficulties –**
 - i. **Receptive** (e.g. deafness, cognitive impairment, autism spectrum disorder) and/or
 - ii. **Expressive** (e.g. cerebral palsy, autism spectrum disorder)
3. **When unsure of ability to understand assume competence and adjust accordingly.**
It is more appropriate and respectful to assume competence than assuming a lack of understanding.
4. **If uncertain ASK about communication preferences/style/techniques**
 - i. *How does s/he say yes/no?*
 - ii. *Does s/he use a communication device or aid?*
5. **Use appropriate and respectful:**
 - **Language:** simple, clear words & short uncomplicated sentences.
 - **Visual information:** pictures, diagrams, signs, gestures.
 - **Tone & volume:** a respectful approach reflects your degree of familiarity with the person, their age and the context of your interaction.
 - **Interpreter** if required.
6. **Wait for response.**
*Allow person **time** to listen, process what you say and respond. **DONT RUSH!***
7. **Check understanding in the person's own words**
Do not simply ask "do you understand?" (Most people say "yes"!)
Remember: receptive language may be better than expressive language (or vice versa).
8. **Be honest and take responsibility for communication breakdowns**
*e.g. I'm sorry I'm not understanding. **NEVER PRETEND** to understand!*
9. **If they don't understand – KEEP TRYING. Repeat. Use clear simple words and concepts.**
Say it in a different way. Use different words. Use pictures.
10. **If you don't understand – KEEP TRYING. Try alternative strategies.**
 - i. *Would you say that again please?*
 - ii. *Is there another way you can think of saying it? Could you use another word? Could you show me?*
 - iii. *Is there someone who could help us? Involve family member/carer/support worker if appropriate – remember to **ASK FIRST!***