

FACT SHEET

Working with people with intellectual disabilities in healthcare settings

People with intellectual disabilities are part of communities and access the resources available to all within those communities, including health services.

An intellectual disability is defined as an IQ below 70 and deficits in adaptive behaviour or daily living skills (self-care, communication, community participation).

2-3% of the population have an intellectual disability – that's more than 100,000 people in Victoria -although many fewer than this seek or receive disability specific services. All healthcare professionals will therefore provide services to people with an intellectual disability, and need to understand some key points in order to provide high quality care to this group.

Implications of intellectual disability

People with intellectual disability:

- learn and process information more slowly; and
- have difficulty with abstract concepts such as money and time and with the subtleties of interpersonal interactions

The kind of support and assistance they require depends on:

- their cognitive ability;
- the expectations on them within particular environments; and
- whether they have other developmental disabilities such as cerebral palsy, autism and or sensory impairments.

Each person is unique, regardless of IQ, and each will have their own personality and areas of ability and areas of difficulty. Arbitrary categories of mild, moderate, severe and profound levels of intellectual disability are defined on the basis of IQ and these give some guide to the level of support someone might need, but the way that person functions in their life will depend on many other factors. Personality, coping strategies, the presence of other disabilities (motor, social or sensory), as well as the support provided to them by their family, friends and community all contribute to the ways in which an individual engages with others and fulfils their community roles.

Someone with a mild intellectual disability (IQ 50-70) (IQ 50-70) may learn to read and write (depending on available educational opportunities). Most people have important relationships in their lives and contribute to their families and their communities. Some people live and travel independently while others require support and assistance in handling money, and in planning and organisation their lives. Many people have a job, in either open or supported employment, Some people marry and raise children with the support of their family, friends and the service system. Their mild intellectual disability means that they will have trouble with academic learning and their reading and writing may be at a basic level. Some people have not had the educational support they needed and may not be able to read or write – many are self conscious about this and so sensitivity is required when requesting people read information or complete written forms for example. Many people find the subtleties of interpersonal relationships and social rules

difficult to fully understand (particularly as adolescents) and many therefore inadvertently transgress social boundaries.

Someone with a moderate intellectual disability (IQ 35 – 50) will also have important relationships in his/her life and will probably form valued and lasting friendships and enjoy a range of activities with their families, friends and acquaintances. With specific training many people learn to travel on regular public transport routes, but 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) and many benefit from visual prompts, such as daily timetables and pictures used in communication systems. People with a moderate intellectual disability will need lifelong support in the planning and organisation of their lives and activities, as well as in the handling of money. Their ability to be independent in personal care tasks, such as toilet hygiene, dressing and bathing, will depend on their 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** will require lifelong assistance in personal care tasks, communication and support and assistance in accessing community facilities and services. People with this level of disability usually recognise familiar people and may have strong relationships with key people in their lives. Most will have little or no speech and will rely on gestures, facial expression and body language to communicate their needs or feelings. 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 a cup itself, may be used in conjunction with the spoken question, “Would you like a drink?”

Barriers to good health care

People with an intellectual disability encounter a number of specific barriers to good health care. For instance, their:

- cognitive difficulties may lead to **difficulties understanding** the importance and long term implications of healthy diet, lifestyle choices, and disease screening’
- limited **literacy** may mean they miss out on health information in magazines, books and public health campaigns;
- **social and financial** situation may lead to difficulty implementing strategies for maintaining a healthy diet, appropriate exercise and health monitoring;
- **communication difficulties** between patient and doctor may lead to difficulty in the reporting of symptoms and past history;
- communication and cognitive issues in relation to **transport** may lead to difficulties in independently accessing medical services and/or independently following through on management recommendations;
- **reliance on carers** may lead to feelings of dependence and powerlessness in health care settings;
- **carers** may not know or be able to provide an accurate and reliable history of the person’s symptoms or previous medical care;
- carers may misinterpret or fail to implement management strategies suggested by health professionals – including arranging appropriate follow up and review; or
- **health professionals** and carers may overlook the need for, or rely on others to arrange, regular health checks and reviews.

Strategies for providing good health care to people with an intellectual disability

1. Attitude

- Convey your respect for the person with the disability through your verbal and body language.
- Address the person and use a tone of voice consistent with their age – ie speak to an adult as another adult.

2. Communication

People with disabilities have a right to the same courtesy any other person can expect. Some may bring a family member, support worker or advocate to the consultation, but the person themselves should always feel that they are the primary focus of the communication.

Receptive communication:

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

- **Speak more slowly** and leave pauses for the person to process your words.
- Speak **directly** to the person concerned, and ensure they feel central to the consultation.
- Speak in **clear short sentences**. Pause frequently to enable the person to process what you are saying. Don't use long, complex words, technical words or jargon.
- Ask **one question at a time** and provide adequate time for the person to formulate and give their reply.
- If it is necessary to obtain the **history from the carer** maintain the focus on the person with the disability through your eye contact, body language and/or touch.
- If the person uses a **communication device**, then ensure they have access to it, read the directions (usually on or in the device or book) and use it with them.

Expressive communication:

People with an intellectual disability may also have trouble expressing their thoughts or feelings. This may be because 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, when talking with someone with an intellectual disability to keep the following points in mind:

- Provide plenty of **time** for the person to reply, comment and formulate their questions or answers.
- You may need to **explore** their question with them to uncover what it is they are concerned about or are asking.
- **Visual cues** – such as objects, pictures or diagrams – and facial expression and body language may all be helpful in understanding what they are saying.

When you can't understand.

There may 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 for instance);
- if they have a **communication aid** (a book or board) that could help you understand;
- if you could ask an **accompanying support worker**/family member (if present) to help you understand;
- to show you how they say “**yes**” and “**no**” – and then ask yes/no questions to identify what it is they are saying.

If you still can't understand, show respect for the person and acknowledge the importance of their message by apologising for failing to understand them.

Never pretend to understand when you do not – this is extremely disrespectful to the person concerned, and devalues their communication.

When 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 or formulate a communication to you, that is, they may not be able to communicate intentionally. However, they, like everyone else, will communicate through their facial expression, body language and behaviour. It may be clear that a person finds a sensation unpleasant from their grimace and drawing back; or that a person is cold when they shiver and goose bumps appear on their arm.. Whether or not someone can communicate intentionally they are entitled to respect and care. Although the history will, in this case, be given by an accompanying family member or support worker, the person themselves should be maintain a central place within the consultation and be included in the discussion through the use of the health professionals eye contact, body language and touch.

(For more communication tips see the accompanying sheet)

3. Working with carers

- Many **people who have a disability** will require the assistance of carers (family members or support workers) to access and participate in the consultation and follow up on the management recommendations.
- **Family members** may have an extensive knowledge of the person's past history and are a very valuable source of information.
- **Support workers** have training and expertise in working with people with an intellectual disability, but do not have healthcare training. Support workers may change frequently during a person/s life and so may not know about the person's previous experience.
- **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 clearly stated and written down to ensure accurate communication with all those involved.
- **Regular review** should be arranged to ensure management recommendations are achieving the outcomes anticipated.

4. Health promotion and disease prevention

- Issues of 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 use, diet, exercise and screening tests as indicated in people of a similar age in the general population

Communication tips that may help when talking with someone with an intellectual disability

- 1. Ensure you have the person's attention**
(address by name, use eye contact and/or touch).
- 2. When unsure of ability to understand assume competence**
& then adjust accordingly. This is more appropriate and respectful than assuming a lack of understanding.
- 3. If uncertain, ask about communication style/techniques**
(forms of yes/no, use of communication aid).
- 4. Use appropriate:**
 - **Language** i.e. *simple, clear words & short uncomplicated sentences.*
 - **Visual information** e.g. *pictures, diagrams, signs, gestures, miming.*
 - **Tone & volume** *for the person & the situation (respectful).*
- 5. Wait for response.**
*Allow person time to listen, process what you say and respond.
Don't rush.*
- 6. Check understanding in own words**
*Do not simply ask "do you understand?"
Remember: receptive language may be better than expressive language or vice versa.*
- 7. Be honest and take responsibility for communication breakdowns**
*(e.g. I'm sorry, I'm not understanding what you're telling me).
Never pretend to understand!*
- 8. Try alternative strategies.**
Is there another way you can think of saying it?
- 9. Repeat process if required.**
- 10. Involve accompanying family member/carer /support worker**
.. if appropriate and with permission.