

Working with people with intellectual disability

What is intellectual disability?

Intellectual disability is a form of cognitive disability that occurs during development though can be diagnosed at any age. Some causes include genetic conditions (e.g. Down syndrome, Fragile X syndrome, Foetal alcohol spectrum disorder) and issues during pregnancy, birth or childhood.

Each person with intellectual disability is unique, with different strengths and ways of accessing the community. People with intellectual disability may experience differences in intellectual function (affecting learning, problem solving and judgment) and adaptive function (affecting social and living skills).

Intellectual disability can be defined by [level of functional impact](#) (mild, moderate, severe and profound) and may indicate the support someone needs.

Consumer quote

“Give me the time and respect I deserve. Talk to me, not everyone else in the room.”

Reasonable adjustments

A **reasonable adjustment** is a change to standard processes, practices, procedures, policies, systems, communication equipment and/ or environment that supports equitable access to safe, effective and patient-centred treatment and care.

It is one way that you can enable me to participate in my care and improve my health outcomes.

Support me to express myself

- Plan for a longer appointment to allow me time to be understood and for me to understand treatment options and make decisions.

- Become familiar with any communication devices I use (e.g. electronic device, book, board) prior to my appointment. Ensure I have access to my equipment during my inpatient stay or during my appointment.
- Ask me one question at a time and allow time for me to respond. Ask yes/no questions if you need to clarify what I am saying. Ask me to show you how I say “yes” and “no”.
- If you are having trouble understanding me, ask me to repeat what I said, or ask me to say it another way. Do not pretend to understand.
- Where possible, utilise staff members who may already have a good relationship with me. This helps me to feel comfortable and communicate more easily.

Adjust your communication style to suit me

- Ask me about my communication needs and preferences because everyone is different. Speak to me clearly, using simple language. Avoid jargon and technical terms.
- Pay attention to my body language and facial expressions. Be mindful of your own body language and maintain eye contact with me.
- Use images and diagrams to help me understand. Use techniques such as the Teach Back technique to check if I am clear about any decisions or information. If you think I don’t understand, explain it in a different way.
- Provide me with resources and instructions in low literacy and plain language formats, such as [Easy English \(also known as Easy Read\)](#). Here are some examples: [‘Say Less, Show More’ clinical resources](#), [Australian Charter for Healthcare Rights](#), and [COVID-19 resources](#).

Understand and respect my rights and care preferences

- Check if I have any physical access needs such as space to use my power chair. I may also have hearing or vision accessibility requirements.
- Speak directly to me, rather than talking about me as if I’m not there. Involving my carer or family members in the discussion is important but remember to speak directly to me when asking questions or explaining about my health care.

- Don't make assumptions about my health or my care preferences. If you are unsure, ask me. Make sure you are up to date with my latest treatments and medications.
- Take my health care concerns seriously. Do not overlook key health issues just because I have an intellectual disability. Listen and allow time for me to express my concerns.
- Check that I can communicate my needs during my hospital stay. For example, can I use the buzzer to alert hospital staff? Do I have my hearing aids?
- Check my basic needs such as toileting, thirst, and hunger are met. Ask if I need a quiet and calm environment.
- Watch for things that make it difficult for me to eat, including if I have difficulty swallowing certain foods.

Work with me to plan my comprehensive care

- Take time before meeting with me to adequately review my medical history. Assess my safety and care needs to avoid harming me.
- Ask my carer about my usual behaviour, especially if I do not speak verbally. I may communicate stress or discomfort through changes in my behaviour. Help me to manage my behaviours using comfort items and activities.
- Seek advice from my carer or family members about how to provide me with good care. Ask for my latest care documentation, such as my Positive Behaviour Support Plan or health passport.
- Develop a comprehensive care plan for me and ensure that it is shared amongst my care team and services.

Support me to make my own choices and look after my health

- Ensure that I, and my family/carer, understand the prognosis and what options are available for my treatment plan. Explain any follow up appointments that I may require or any further actions I should take.
- Communicate to me in a way that suits my abilities and preferences, so I am empowered to make my own choices where possible.

- If necessary, ensure a substitute decision maker has sufficient information to provide informed consent for me.
- Use memory aids and other methods to support me to manage my own treatments and to take my medications.
- Make sure I am aware of the hospital support roles available to me such as Disability Nurse Navigators and social workers. Check if I would like them to help me navigate the healthcare system and my treatment plan.

More information

- [Guidance and resources for implementation of the NSQHS Standards](#)
- [NSW Health 'The Essentials' resources](#)
- [Down Syndrome Australia information for health professionals](#)

Online training

- [Every Nurse's Business](#)
- [Queensland Centre for Intellectual and Developmental Disability \(QCIDD\) ABLEx training](#)
- [Access for All](#) training from Check-UP (General disability training for health providers)

Adapted from material developed by Metro South Health, Health Equity and Access Team.