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Lecture Reference Book

For use with the intellectual disability lecture plans

Intellectual Disability Health Capability Framework Resources



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Description

This Lecture Reference Book is part of a suite of resources designed to support the [Intellectual Disability Health Capability Framework](#) (the Framework). The Framework aims to equip pre-registration students studying health, allied health, dentistry and other health-related disciplines with the required core capabilities to provide quality health care to people with intellectual disability.

This resource should be used in conjunction with the associated Lecture Plans and Tutorial Activities, which have been developed to introduce the first two capability areas in the Intellectual Disability Health Capability Framework. The lecture plans outline key teaching points, and this Lecture Reference Book provides more detailed information on each of the lecture topics. This Lecture Reference Book also provides background information that educators can use to create lecture materials for their discipline.

Additional resources are also available for educators to support integration of the Framework into existing curricula. Please see the [Intellectual Disability Health Capability Framework and education resources](#) to view all available resources.

Glossary

- **accessible** – Environments, facilities, services, products and information that people are able to use and interact with in a way that suits their needs. [1]
- **adaptive functioning** – Age-appropriate behaviours that people need to live independently and to function safely and appropriately in their everyday life.
- **Augmentative and Alternative Communication (AAC)** – Methods of communication personalised to enable the participation of a person who may experience barriers to spoken communication. They include unaided forms, such as eye contact, gestures, facial expression, vocalisations and sign language, and aided forms that use devices to communicate. [1]
- **behaviours of concern** – Behaviours of which the intensity, frequency or duration negatively impacts the quality of life or safety of the person or those around them and are likely to result in the person experiencing aversive responses, including being restricted or excluded. [2]
- **capacity to consent** – A person's ability to make decisions. A person is generally presumed to have capacity if they can understand facts and choices involved, weigh up consequences, and communicate their decisions. Legally, adults are presumed to have capacity to consent until otherwise indicated. Capacity to consent is time and situation specific. [3]
- **diagnostic overshadowing** – The misattribution of symptoms to the person's disability rather than to a health or mental health concern. [4]
- **Easy Read** – Easy Read materials adapt standard information into a briefer copy using easier-to-understand language and pictures to support comprehension of the text.
- **intellectual disability** – A lifelong condition that affects a person's intellectual skills and their behaviour in different situations. People with intellectual disability can have difficulties in communication, memory, understanding, problem solving, self-care, social and emotional skills, and physical skills. [5] Intellectual disability originates in the developmental period (before 18 years of age). [6]
- **person-centred approach** – This approach puts the person with intellectual disability at the centre of planning and decision-making about their own support and services and encompasses the principles of equality, choice, and inclusion.
- **reasonable adjustments** – In health care include policies, processes, systems and communication that adjust for the needs of the person with intellectual disability. Reasonable adjustments prevent direct and indirect discrimination against a person with disability. [7]
- **supported decision-making** – Processes and approaches that assist people to make a decision, including giving them the tools they need to make the decision for themselves. Supported decision-making does not mean making a decision for, or on behalf of, another person. [1]
- **trauma-informed approach** – This approach considers the impact of trauma on individuals and focusses on providing an environment in which recovery can occur, and re-traumatisation does not occur.

Lecture 1: Intellectual disability health

Section 1: What is intellectual disability?

Lived experience presentation

The inclusion of a lived experience presentation as part of intellectual disability health education offers a unique insight into the experience of people with intellectual disability in health care and is strongly recommended. Ideally, arrange for a person with intellectual disability (and potentially a carer or family member of a person with intellectual disability) to attend for a live or online presentation. If this is not possible, a good alternate option is to see if a person with lived experience could record a video of themselves talking about their experiences to show in class. If neither of these options are possible, consider finding a video online that could be used – for example, Maria Heaton's [A Family Perspective](#). Videos such as this can also complement in-person presentations.

It is important to note that organising a lived experience presentation is a process that requires ample time, preparation and consideration. For more guidance on engaging with lived experience educators, see the Co-education Toolkit on the [Framework and education resources collection](#) page.

Intellectual disability and its prevalence and causes

What intellectual disability is

Intellectual disability is a lifelong condition that affects a person's intellectual skills and their behaviour in different situations. People with intellectual disability can have difficulties in communication, memory, understanding, problem solving, self-care, social and emotional skills, and physical skills. [5]

Diagnostic criteria are provided by definitions in the Diagnostic and Statistical Manual of Mental Disorders (DSM-5-TR) [6] and the International Classification of Diseases (ICD-11). [8] According to these criteria, a person has intellectual disability if the following three features are present:

- below average intelligence (e.g., as demonstrated by an IQ score of 70 or less)
- deficits in adaptive functioning
- onset during the developmental period (in Australia, this is regarded as before the age of 18).

If the onset of below average intelligence and deficits in adaptive functioning occur after the age of 18, this is usually due to acquired brain injury or a neurodegenerative disease (e.g., dementia). In these cases, it is not considered intellectual disability and is instead referred to as a cognitive disability or impairment.

Intellectual disability is a subset of developmental disability, meaning all people with intellectual disability have developmental disability, but not all people with developmental disability have intellectual disability. For example, some people with cerebral palsy, autism or spina bifida may not have intellectual disability.

What adaptive functioning is

Adaptive functioning is the term used to describe the age-appropriate behaviours that people need to live independently and to function safely and appropriately in their everyday life.

Adaptive functioning involves different types of skills (DSM-5): [6]

- conceptual skills, in the areas of language, literacy or number concepts (like money and time) and self-direction.
- social skills, such as interpersonal skills, social responsibility, self-esteem, gullibility, social problem solving, the ability to follow rules and to avoid being victimised.
- practical skills, or skills of daily living like personal care, health care, travel/transport, schedules and routines, safety, use of money, use of the telephone.

Adaptive functioning is important to consider because two people with the same IQ may function differently in everyday life.

Levels of intellectual disability

It can sometimes be helpful to categorise a person's level of intellectual disability. For example, it can help determine eligibility for services or provide a general indicator of the person's support needs.

A common way of classifying the level of intellectual disability is based on IQ. However, the range of IQ scores for each level is broad, and there is overlap between levels. Therefore, current ways of categorising a person's level of intellectual disability take into account their level of adaptive functioning.

Table 1. below details one way that the level of intellectual disability can be categorised. [9]

Table 1: Levels of intellectual disability

Level	IQ categories	Daily functioning
Mild	IQ 50 to 70	<ul style="list-style-type: none">• Can learn to read and write.• Can live reasonably independently, may have a job and drive a car.• May have difficulty with subtle social conventions, understanding risk and managing money.• Language acquisition can take longer, but can communicate well once learnt.• Can form many interpersonal relationships.
Moderate	IQ 35 to 50	<ul style="list-style-type: none">• Support required for planning, organisation and personal care.• May be able to travel alone in familiar settings.• Delayed language acquisition. May benefit from additional communication supports.• Can form important enduring relationships.
Severe	IQ 20 to 35	<ul style="list-style-type: none">• Require daily assistance, particularly with communication, personal care, and safety.• Largely non-verbal communication; can communicate about straightforward things.• Close bonds with key people.
Profound	IQ less than 20	<ul style="list-style-type: none">• 24-hour intensive support required.• Communication is largely non-verbal.• Close bonds formed with key people, but interactions limited by sensory and physical impairments.

Prevalence of intellectual disability

The prevalence of intellectual disability varies across studies but affects about 1-3% of the Australian population. [10-12]

Causes of intellectual disability

- There are many different causes of intellectual disability, and often there is more than one factor which leads to its development. Many causes of intellectual disability also cause other disabilities, impairments or health problems.
- In about half of people with intellectual disability, a cause can be found.

One way of classifying causes of intellectual disability is by whether they occur prenatally, perinatally or postnatally. Some of the possible causes of intellectual disability are listed below.

Prenatal causes of intellectual disability

- Single gene abnormalities – these can include inborn errors of metabolism such as phenylketonuria (PKU).
- Polygenic causes (multiple genes involved, often the deletion or otherwise altered functioning of contiguous genes) – e.g., William's syndrome.
- Chromosome disorders – e.g., Down syndrome, Fragile X syndrome. Fragile X syndrome is the most common known inherited cause of intellectual disability.
- Exposure to teratogens (negatively affect a foetus) – e.g., alcohol (causing foetal alcohol syndrome) and some anti-epileptic medications.
- Infections during pregnancy such as cytomegalovirus (CMV), rubella or toxoplasmosis.
- Developmental brain abnormalities such as lissencephaly (characterised by an absence of folds in the cerebral cortex and abnormally small head) and spina bifida (the incomplete development of the spine and spinal cord).

Perinatal causes of intellectual disability

- Prematurity – babies born prematurely have a higher risk of intellectual disability. The more premature the baby is born, the higher the risk of intellectual disability. [13]
- Intra-ventricular haemorrhage (IVH) in newborns may occur in premature babies and babies with low birth weight. More severe IVH may cause intellectual disability. [14]
- Hypoxic-ischaemic encephalopathy (brain injury which occurs when the infant's brain does not receive enough oxygen during birth).

Postnatal causes of intellectual disability

- Various conditions which can impact young infants may cause intellectual disability. These include conditions such as
 - hypoglycaemia
 - kernicterus (a complication of severe jaundice in newborns)
 - infections such as encephalitis (swelling of the brain) and meningitis (swelling of the membranes protecting the brain and spinal cord)
 - hypoxia, such as can be caused by near-miss sudden infant death syndrome or near drowning experiences.
- Traumatic brain injury may cause intellectual disability. Note that if the injury occurs after the age of 18, any subsequent impacts would not be considered intellectual disability but instead cognitive disability or impairment.
- Exposure to toxins, such as lead or mercury poisoning.
- Experience of severe malnutrition or dehydration.

Section 2: Health status of people with intellectual disability

Setting the scene

It is recommended to play the [ABC 7:30 Report on preventable deaths](#) video from [0:00 to 4:36]. This video reports on the study finding that people with intellectual disability are twice as likely to experience preventable deaths.

Health status and common health conditions

Health status

Health outcomes are significantly worse for people with intellectual disability, compared to the general population. People with intellectual disability also experience higher levels of premature and potentially avoidable deaths. [15] Over the past few decades, there have been substantial advancements in how people with intellectual disability are integrated into everyday life and their communities. [16] This change is reflected in health systems – such as the shift from the historical separation of people with intellectual disability, to the expectation that all people may access mainstream health services. [16, 17] Despite these advances, the [Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability](#) found that “people with cognitive disability have been and continue to be subject to systemic neglect in the Australian health system”. [18] Health and disability supports also remain mostly siloed with a lack of cross-sector capacity building. [19]

Common health conditions

People with intellectual disability can be at a higher risk of experiencing a range of physical and mental health conditions. Therefore, the health care of people with intellectual disability is relevant to all disciplines. For example, in one study based on records from general practice databases, people with intellectual disability, compared to people without intellectual disability, were: [20]

- **15 times more likely** to experience epilepsy
- **14 times more likely** to experience musculoskeletal impairment
- **3 to 4 times more likely** to experience mental illness
- **3 times more likely** to experience hearing impairment
- **3 times more likely** to experience obesity
- **2 times more likely** to experience dermatitis, eczema and acne

In addition, in studies which compared people with intellectual disability to the general population, people with intellectual disability were:

- **Up to 21 times more likely** to experience vision impairment [21]
- **8.5 times more likely** to experience dental disease [22]
- **2 to 3 times more likely** to experience heart failure [23]
- **2 to 3 times more likely** to experience diabetes [24]

In addition to this, many syndromes are also associated with specific health problems. For example, people with Down syndrome have an increased risk of cataracts, vision and hearing impairments, thyroid disorders, seizures, coeliac disease, and blood disorders. [25]

Because people with intellectual disability are at an increased risk of such a range of conditions, it is vital that health, allied health and dental health professionals working in all disciplines are familiar with health conditions in this population and know how to engage with people with intellectual disability.

Determinants of health for people with intellectual disability

People with intellectual disability have a greater likelihood of having multiple health conditions and a reduced ability to manage their own health due to challenges monitoring their health and recognising that changes within their body, discomfort, or pain may signal the need for medical attention. There are many factors that can increase the risk of a person with intellectual disability experiencing physical and mental health problems. These include:

Greater social risks

- People with intellectual disability are at greater risk of social isolation due to having less opportunities to take part in social and employment activities.
- People with intellectual disability and their families are at greater risk of financial stress. [26]
- Some people with intellectual disability may have few family members and friends to act as their support network.
- Stigma around the abilities of people with intellectual disability can increase social isolation.
- People with intellectual disability may have reduced social and interpersonal skills.
- People with intellectual disability may have difficulties in expressing and managing grief and other negative emotions.

Psychological risks

- People with intellectual disability may have diminished resilience due to challenges utilising coping strategies (often due to executive functioning issues).
- They may have a lack of confidence in their own skills and abilities.
- Some people with intellectual disability have difficulties understanding and communicating their emotions.
- Some people with intellectual disability can feel overwhelmed or anxious due to difficulties in processing multiple stimuli (e.g., loud sounds, a lot of information).
- A higher likelihood of experiencing of trauma and negative life events.
 - **Trauma-informed approach:** Trauma informed care considers the impact of trauma on individuals and focusses on providing an environment in which recovery can occur, and re-traumatisation does not occur. A trauma-informed approach to health care is particularly important when working with someone with intellectual disability, as people with intellectual disability have a higher likelihood of having experienced trauma (including bullying, neglect, and abuse) and often have a lack of control over their own life.

Physical health risks

- Some causes of intellectual disability are associated with physiological differences that can increase the risk of illness.
- People with intellectual disability have a higher likelihood of experiencing co-existing physical and mental conditions, which can cause difficulties in carrying out daily tasks and affect self-esteem and motivation.

Lifestyle factors

People with intellectual disability have a higher likelihood of:

- being underweight or obese [27]
- doing less than the recommended amount of exercise compared to people without intellectual disability [28]
- sleep problems. [29]

Environmental factors

- A person with intellectual disability's wellbeing may be affected by their living conditions. For example, they may not have the freedom to choose where to live, or a person's accommodation may not provide the supports that they require.

Protective factors

Although there are elevated risk factors for people with intellectual disability, there are many protective factors that can attenuate these risks. Social and community group engagement, regular visits to a GP and any other relevant health professionals, as well as maintaining a healthy lifestyle, can support people with intellectual disability in minimising or avoiding many of these risks.

Section 3: Reasonable adjustments

What reasonable adjustments are

Reasonable adjustments are policies, processes, systems and communication that adjust for the needs of the person with intellectual disability. [7] Reasonable adjustments to practice are an essential part of ensuring that health care is accessible to people with intellectual disability and that they are included in decisions about their health care.

Reasonable adjustments that can be made to practice

Reasonable adjustments will vary based on the individual and the complexity and nature of the decision they need to make. To ensure preparedness for providing reasonable adjustments, it can be useful to review any background information known about the person prior to an appointment – such as their medical history and decision-making capacity.

Possible reasonable adjustments include: [30]

- Asking what communication method(s) the person commonly uses and prefers.
- Involving others, such as carers, family, or support workers (if the person agrees).
- Taking time to build rapport with the person.
- Ensuring that the person is told at each step of the assessment or examination about what will happen.
- Providing relevant information in a way that fosters supported decision-making, e.g., utilising accessible information (e.g., Easy Read) and using health records such as [My Health Matters](#).
- Minimising wait times for the person, and if delays are unavoidable, ensuring clear communication to manage the person's expectations around how long they will have to wait.
- Allowing more time for appointments, including sufficient time for breaks during longer appointments.
- Consider physical access and sensory needs, and how best to ensure the person is comfortable, especially when encountering unfamiliar or changing environments, routines, procedures, and people. For example, arranging for a quiet room so the person does not have to wait for an appointment in a noisy waiting room.
- Engaging in behaviour support strategies to support the person to avoid or de-escalate distress. Speak with carers, family members and supporters to see if the person has a behaviour support plan.

Lecture 2: Communication

Section 1: Communication challenges faced by people with intellectual disability

Communication involves the sending and receiving of verbal (e.g., language, speech sounds) and non-verbal (e.g., expressions, pictures) messages. [31] This includes behaviour as a form of non-verbal communication. Good communication is an essential part of effective health care for all people, with or without intellectual disability. It is also an essential part of a person's capacity to consent, and their ability to make decisions, which are important to prioritise in intellectual disability health care. Some people with intellectual disability have difficulty in expressing themselves and understanding others due to communication challenges, especially those with severe or profound levels of intellectual disability. This can be a barrier to seeking and receiving appropriate health care, as it can make it difficult for a person to receive and express important information about their health, as well as cause issues in how they are able to engage in decision-making in a health care setting. Communication difficulties can lead to people with intellectual disability having poor health literacy, not utilising prevention measures to support their health, and contributes to the underdiagnosis of medical and psychiatric disorders.

Examples of communication difficulties people may experience include the following.

- Difficulties in communicating needs or communicating that they are in pain or feel unwell. This can include difficulties in being able to communicate where pain is and the type of pain they are experiencing (expressive communication).
- Difficulties in understanding what is being communicated by other people, such as instructions around how to take medication (receptive communication).
- Difficulties in communicating with a support person or health professional who is not trained in/aware of the person's preferred method of communication.
- Difficulties in completing health assessments which rely on verbal questions and answers.

Section 2: General principles for communication

Preparing for a consultation

It is important to prepare for a consultation with a person with intellectual disability. Health professionals should ask the person or their carer, family member, or support worker about the person's preferred communication methods, considering the following areas.

- The type of language a person uses (e.g., verbal or non-verbal; words, phrases or whole sentences).
- If the person uses any communication supports such as picture charts or apps.
- Any behaviours that the person uses to communicate.
- The types of information they understand and to what extent, e.g.:
 - Do they understand all or most of what people say to them?
 - Do they prefer Easy Read information, or the use of pictures or diagrams?

- Easy Read is a method of presenting information in a simplified way with short-sentences and no jargon, accompanied by pictures.
- How others, such as family, usually support the person when they need to make a decision.
- If the person tends towards:
 - suggestibility: giving the reply that the person thinks is expected by the interviewer or
 - acquiescence: giving an affirmative answer to every question.

Person-centred approach

A person-centred approach maximises the person's involvement in decision-making and seeks to understand the person and their situation and inform health care to be best tailored to the individual and their needs/preferences. Communication is an essential part of a person-centred approach.

- Communication considerations when using a person-centred approach include the following.
- The person's communication preferences.
- A combination of different communication approaches which are beneficial for, and preferred by, the person.
- Adequate communication training for the person's health care team.
- Involvement of others, including the person's carer, family member or support worker.
- Regular review of communication methods that are being used.
- Resources such as [My Communication Passport](#).

Section 3: Adapting communication

Communication strategies

- Adapting verbal communication to support understanding e.g.:
 - breaking concepts down
 - providing information at a slower pace than usual
 - asking questions to check the person's understanding.
- Using time anchors instead of referring to chronological time. Anchoring to events that have occurred in a person's life can be useful when a person has difficulties understanding conventional time concepts. For example, instead of asking "how long has your head hurt?", asking "did your head hurt when you went to day group?".
- Be mindful of how questions are framed. Consider the impact of asking open or closed questions e.g., consider the possibility that the person might demonstrate suggestibility or acquiescence.
- Avoid moving between unrelated topics; instead try following topics the person wants to discuss.
- Avoid hurrying to complete procedures (such as an assessment) in one session; instead aim to finish with the person feeling that they were heard and that their needs were met.

Augmentative and Alternative Communication

Augmentative and Alternative Communication (AAC) refers to a range of techniques used to assist in communication. These can be either unaided or aided. Below are a range of techniques that can be used.

Unaided AAC

- Eye contact
- Facial expression
- Gestures (e.g., pointing and other body movements)
- Signing
 - Natural sign language
 - Unique signals (someone's personal signs)
 - Key word signing – a system which combines signing and natural gesture. Full grammatical sentences are spoken while the key words are signed. Facial expression and body language support the message.
 - Signed language
 - Finger spelling

Aided AAC

- Real objects (e.g., using a glass of water to show how medicines should be taken)
- Visual representations of words/concepts (e.g., photos, pictures, symbols)
- Written text – i.e., presenting accessible information such as plain language versions or Easy Read format.
- Templates for appointment reminders, care plans, medicinal information etc.
- Communication apps.

Section 4: Behaviour as a form of communication

As behaviour has meaning, it is a form of communication. It is useful to view behaviour as communication even when the person has no deliberate intent to communicate or share information about their subjective state. Behaviour is often interpreted automatically when understanding a person, however sometimes behaviours can be interpreted based on our own personal or cultural perspectives, or misunderstanding the reason for the behaviour.

Communication through behaviour includes behaviours of concern. These are behaviours that negatively impact the quality of life or risk the safety of the person and those around them, and are likely to result in the person experiencing aversive responses, including being restricted or excluded. [2] For example, if a person is exhibiting absconding behaviours (running away), they might be afraid. If we interpret the person's needs correctly, we are better able to respond to them and thus resolve the behaviour (rather than suppressing the behaviour).

Regardless of the behaviour, it is important not to assume or draw conclusions too quickly, and instead to consider what the person could possibly be communicating.

- What behaviour might be communicating

- Psychological symptoms
- Emotions
- Physical health problems
- States such as pain, discomfort or hunger
- Something about the situation that the person is in e.g., the situation is unfamiliar and/or frightening.

Table 2. Interpreting behavioural expressions

Verbal expression of state	Possible behavioural expression equivalent
"I'm pleased to meet you"	Offering a hand to shake; offering a hug or kissing the other person's cheek.
"I'm happy and excited"	Smiling; jumping up and down and clapping.
"I'm anxious"	Avoiding eye contact; fidgeting; retreating/leaving a situation.
"I feel nervous and I don't want to interact with you"	Avoidance behaviour e.g., crossing to the other side of the street, walking away or avoiding eye contact.
"My stomach hurts"	Slouching/other changes in posture; holding onto stomach; having a lower tolerance than normal for stimuli the person finds annoying/aversive; groaning.
"My head hurts"	Holding onto head; hitting head.
"I'm feeling angry"/ "I want this door to be closed"	Slamming a door.

- Behaviour is often ambiguous – one behaviour can have several different possible meanings. Having more information about a person, including personal preferences, history, and details about their situation can make accurate interpretation easier.
- A person may communicate differently depending on the situation and how they are feeling – for example, a person who usually uses speech to communicate may not do so when they are upset and may instead use body language to communicate.
- Atypical presentations and behavioural equivalents
 - Greater severity of intellectual disability increases the likelihood of atypical presentation of symptoms.
 - Behavioural equivalents are the expression of mental illness through behaviour rather than through verbal description.
- Diagnostic overshadowing – when symptoms of illness are mistaken as part of the person's intellectual disability. Consider changes to behaviour or presentations of behaviours of concern which could indicate pain, or physical or mental health conditions e.g., dental abscess, constipation, anxiety, depression. [4]
- Examples of behaviour as communication – e.g., [Video demonstrating behaviour of concern as communication](#).

Section 5: Communication to reassure

Recognising that people with intellectual disability may have differing levels of understanding of health care situations and procedures is important. Communicate directly with the person in a way that seeks to include them in health care discussions and inform them of what is occurring during health appointments and procedures and their purpose, giving a sense of control and improved comfort. It is important to use a trauma-informed approach, as many people with intellectual disability may have had previous negative experiences within a health care setting. [32] Therefore, care should be taken to make sure that they feel comfortable and safe. This can include the following.

- Taking time to establish rapport and help the person relax.
- Explaining to the person what will happen during an appointment, or where they will go next for a test in hospital and narrating what is happening at each step.
- Asking the person if they have questions.
- Reassure the person that they are in a safe place (particularly if in a stressful situation, e.g., an emergency department at a hospital).

Each individual will have varying levels of stress around medical procedures and being in health care settings. It is important to always communicate to reassure and check in with how the person is feeling.

Consider location and timing factors that can support communication

Location

- Find out if there are certain environments that the person feels more comfortable in, and accommodate where possible.
- Where possible, choose a setting in which the person can be given full attention, with minimal interruptions or background noise/activity.
- Provide warning if changing locations.

Timing

- Find out if a particular time of day is better for the person.
- The person may need more time than other people to make a decision. Give the person plenty of time to think about information, ask questions, and process their own feelings and preferences (along with other ways to support decision-making, such as accessible information). They may need more than one appointment to make a decision. If there are several decisions to be made, consider making different appointments for each decision.

Involve others

- Find out if the person would like someone with them, such as a family member or carer. Support the person to connect with services if needed (e.g., an interpreter for a language other than English, or sign language, to facilitate communication if needed).
 - Consider that the family member or carer that is accompanying the person may also require communication support – e.g., they may not have high health literacy and therefore need certain health concepts explained, or may not speak English. Ensure everyone has the information they require in a way they can understand.

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All information in this publication is correct as at May 2025

