



Diagnostic overshadowing of people with intellectual disabilities

A fact sheet for healthcare and disability workers

This fact sheet is intended to help health professionals and disability workers support people with intellectual disabilities or other conditions such as autism. This resource should be read in conjunction with Li-Ve Tasmania's *Communicating for end of life – a toolkit* and associated resources.

Scan the QR code with your smart device to access *Communicating for end of life – a toolkit*, including practical resources for carers of people with an intellectual disability.



What is diagnostic overshadowing?

Diagnostic overshadowing is when a person's physical symptoms are inadvertently attributed to an underlying intellectual disability by health or disability professionals. This creates a risk that a physical illness may be underdiagnosed or undertreated.

People living with intellectual disability experience higher rates of health inequalities and avoidable deaths due to diagnostic overshadowing than the population as a whole.

Understanding diagnostic overshadowing

Research shows that diagnostic overshadowing is not caused by a lack of care or willingness to help. It can, however, be associated with a lack of knowledge or experience treating or supporting someone with an intellectual disability.

A person with an intellectual disability may exhibit a **change in behaviour** when they experience serious physical or mental illness, pain, anxiety, discomfort, or environmental change. This could be in the form of a new or unexplained behaviour, or an increase or decrease in an existing known behaviour.

Understanding the reasons behind a behaviour change or a new behaviour of a person with an intellectual disability can eliminate the escalation of pain, and reduce hospital admission and avoidable deaths.

Example

A health professional is informed that their non-verbal patient with intellectual disability has started to repeatedly hit their cheek.

The person sometimes exhibits challenging behaviour, and the clinician concludes the cheek-hitting is a normal behaviour for them. However, the person could be trying to communicate a sign of pain – a tooth ache, for example.

Any change in the physical or mental function of a person with an intellectual disability should be taken seriously and new symptoms investigated swiftly.

The University of Hertfordshire website is proactive on the importance of [Annual Health Checks for People with Intellectual Disabilities in General Practice](#). The site includes a list of points to be addressed at patient visits.

More **case studies** of diagnostic overshadowing are available in Mencap's two reports [Death by indifference \(2007\)](#) and [Death by indifference – 74 deaths and counting – 5 years on \(2012\)](#).

Reducing the risk of diagnostic overshadowing

- Take the time to find out and document details of a person's intellectual disability. This includes their skills and limitations, their baseline behaviours and demeanour.
- Perform a detailed physical health history, examination, and tests before excluding a physical health problem.
 - Refer to the [Department of Health - Fact Sheet Health Assessment for people with an intellectual disability](#) and Li-Ve Tasmania's [Stop and Watch](#) tool.
- Notice non-verbal signs that may indicate pain, anxiety, or discomfort. For example, a change in facial expressions, body positions and sounds.
 - Use the [Tips for Communicating with People with Intellectual Disability](#) for guidance.
- Look for new impairments such as hearing loss, visual impairment and [sensory processing disorder](#) – a condition which affects how our brains process sensory information.
- Practice person-centred care by involving people who know the person best, such as carers, family members and disability support workers, to help you know the person and their behaviour. This will also assist in establishing open lines of communication throughout the person's healthcare experience.
 - For support use the [Support Isobar](#) tool.
- Enable health assessments to provide a baseline understanding of a person's health and wellbeing. This helps to ensure that a change in a person's condition or illness is not attributed to the intellectual disability.
- Practice shared decision-making, accountability, communication, coordination and documentation between disability providers and health professionals. This supports hospital admissions and discharge from hospital and enables follow-up if the person cancels or does not attend an appointment.
 - For support use [My Hospital Passport](#), [Medical Appointment Form](#), and the [Care Alert](#) tools.

Improving healthcare access and delivery with TEACH

Making reasonable adjustments when caring for people with intellectual disabilities is another way to avoid diagnostic overshadowing. This means adapting healthcare environments and services to ensure the person feels safe and comfortable, so they receive the same level of care as those without disability.

Use the mnemonic TEACH to help make reasonable adjustments:

- T**ime. Ask for longer medical appointments or an early morning appointment when the waiting room is quieter.
- E**nvironment. It might mean the dentist visiting at home or meeting the individual in casual clothes rather than in gowns.
- A**ttitude. Treat everyone with dignity and respect as an individual.
- C**ommunication. Use accessible information that can be understood. For example, easy-read leaflets, pictures, symbols or sign language.
- H**elp. Listening to family, carers or supporters to know where to get specialist help when needed.

For more information on caring for people with intellectual disabilities, visit [Tasmanian HealthPathways](#) at www.primaryhealthtas.com.au.

References

- University of Hertfordshire – Intellectual Disability and Health Diagnostic overshadowing: see beyond the diagnosis
Hayes, P. 2016. Disability healthcare. Good Practice (6) 10-12
Statement of Professor Julian Trollor. 11 February 2020. Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability
University of Hertfordshire – Intellectual Disability and Health Diagnostic overshadowing: see beyond the diagnosis
University of Hertfordshire- Intellectual Disability and Health. Welcoming a patient with Intellectual Disabilities into General Practice: Reasonable Adjustments in Primary Care
Public Health England. How social care staff can use reasonable adjustments to support the health of people with learning disabilities