

Hospitals note a person's intellectual disability only 20% of the time, so they don't adjust their care

May 3 2022, by Adrian Raymond Walker and Julian N. Trollor



Credit: Tima Miroshnichenko from Pexels

People with intellectual disability only have their disability noted by hospital staff in one in every five hospital admissions, [our new study](#)

[shows](#).

Recognizing someone has a disability is critical to their care. This finding helps explain why many people with [intellectual disability](#) do not get [hospital care](#) that best meets their needs.

Urgent action is needed to make our hospital system safe, effective and tailored to the needs of around [450,000 Australians](#) living with intellectual disability.

A system of neglect

Our [research](#) looked at [historical information](#) from hospitals and disability services in New South Wales between 2005 to 2015 (the most recent accessible data).

We found 12,593 adults with intellectual disability who used disability services in this time. In total, these adults went to hospital 80,960 times from 2005 to 2015. But in only 19,261 of these visits did the hospital recognize the person had an intellectual disability.

Intellectual disability is broadly [defined](#) as a lifelong condition that affects intellectual skills, behavior and the ability to perform everyday tasks.

Intellectual disability exists across a spectrum. People with mild intellectual disability might engage in activities like full time work and sport. People with profound intellectual disability may not be able to communicate and require full time care.

Little has changed in the [health](#) care system to fix this issue since the data in our research was collected.

In 2008, Australia ratified the United Nations [Convention on the Rights of Persons with Disabilities](#), which protects the right to the highest attainable standard of health without discrimination on the basis of disability. But the reality for Australians living with intellectual disability is starkly different.

Right now, the [Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability](#) is looking into problems faced by people with disabilities.

Based mainly on evidence from people with intellectual disability on the [autism spectrum](#), the commission found people with cognitive disabilities [face neglect](#) in the [health system](#). They found people with disabilities experience higher costs, longer waiting lists, physically inaccessible services and complex medical forms.

A person with intellectual disability may experience delayed diagnosis and inefficiency because of communication difficulties. Health professionals may lack the skills to assess and manage medical conditions when intellectual disability is also present.

Poorer care ends lives sooner

Our previous research has shown gaps in [preventative health care](#), [mental health care](#) and in [life expectancy](#). People with intellectual disability die on average 26 years younger than the general population.

Most of this difference in life expectancy is not specifically related to the intellectual disability itself or its causes. Rather, it relates to lifelong health disadvantage, lack of access and failure to manage emerging health conditions.

Potentially avoidable deaths (from conditions that could have been

prevented through individualized care or treatment, like viral pneumonia, asthma, or diabetes) are [more than twice as likely](#) in people with intellectual disability.

Though Australia has one of the [best health care systems in the world](#), people with intellectual disability experience neglect within it.

Ahead of the upcoming national election, [people with intellectual disability](#) are calling out this "deadly discrimination."

How do we improve recognition?

To improve the recognition of intellectual disability when someone goes to hospital, we would like to see a national health disability indicator in the form of a code. When noted on their health records, this indicator would tell the [health care system](#) a patient has an intellectual disability (with the permission of that person), and they might need reasonable adjustments to be made.

This indicator would help make intellectual disability visible in hospitals, and ensure people get the best possible care.

An indicator of this kind is [already used in the U.K.](#) People with disabilities help set up their own indicators to make sure their needs are met.

Reasonable adjustments

Reasonable adjustments are things that need to be done to make health care accessible to a person with disability.

For people with intellectual disability, reasonable adjustments can

include adjusting communication, providing extra time and support, and involving the person in choices and decisions. Research shows reasonable adjustments [improve care](#).

In the U.K., all hospitals must make reasonable adjustments and the person with disability must be asked about [what adjustments they need](#). Hospitals that do not make reasonable adjustments risk losing accreditation and funding.

In New South Wales, hospitals are meant to make [reasonable adjustments for people with disability](#). However, our study suggests most of the time, when a person with intellectual disability goes to hospital, this does not happen because the hospital remains unaware of their needs.

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