

People with intellectual disability at 'unacceptably high' risk of preventable hospitalization

June 14 2021



Credit: Judita Tamošiūnaitė from Pexels

People with intellectual disability are being hospitalized for conditions that could have been adequately managed in primary care or through

prevention—at a rate 3.5 to 4.5 times higher than the general population, according to a study by UNSW medical researchers published today in the *Medical Journal of Australia*.

The researchers say the [high rates](#) of potentially preventable hospitalisations (PPH) are a symptom of the systemic neglect by the Australian [health](#) care system—recently reported by the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability—that people with [intellectual disability](#) experience. The researchers call for urgent systemic action to address this issue.

PPH is defined in the National Healthcare agreement as hospital admissions for conditions where "the hospitalization could have potentially been prevented through the provision of appropriate individualized preventative health interventions and early disease management"—for example, vaccine-preventable conditions such as the flu, chronic conditions like asthma, and acute conditions such as convulsions and epilepsy.

"We already know from international research that people with intellectual disability experience higher rates of PPH—and that they generally face stark health inequalities and barriers to accessing health care," says senior author Professor Julian Trollor from UNSW Sydney's Department of Developmental Disability Neuropsychiatry (3DN).

"But before our study, there hasn't been any research into rates of PPH for Australians with intellectual disability."

To address this evidence gap, the researchers analyzed data collected over 15 years pertaining to 92,542 people with intellectual disability, and compared it to a cohort of the NSW general population.

"Our key finding is that people with intellectual disability in New South

Wales experience higher PPH compared to the general population, which is unacceptable—they are 3.5 to 4.5 times more likely to be hospitalized for a condition that could have been managed through [primary care](#) or prevention," says UNSW lead author Dr. Janelle Weise.

People with intellectual disability were also found to be up to 25.7 times more likely to be hospitalized for convulsions and epilepsy compared to the NSW population—the biggest inequality uncovered in the study.

"And we also found that people with intellectual disability are up to three times more likely than the NSW population to be hospitalized for a vaccine-preventable condition," Dr. Weise says.

"It is critical that we look into why people with intellectual disability are being hospitalized for vaccine-preventable conditions, as we know that failure to vaccinate is also a factor associated with preventable deaths in people with intellectual disability.

"Particularly in light of the COVID-19 vaccine rollout, we need to address the barriers faced by people with intellectual disability to be vaccinated."

Urgent systemic action needed

The researchers say PPH are a marker of poor access to primary and community-based health care.

"But we simply don't have enough research into what actually drives PPH—in the [general population](#), and even less so in people with intellectual disability," says Prof. Trollor.

"That's why we now need to find out why exactly that's happening, and then do something about it—governments, policy makers, services and

professional groups have much work to do to improve health care for people with intellectual disability."

The authors' recommendations include a national population health strategy for people with intellectual disability and mandating reasonable adjustments in Australian health care to meet the needs of people with intellectual disability.

"We also need to equip the [health care](#) workforce in the area of intellectual disability health—and we need to make sure people with intellectual disability and their support networks have the tools to improve their health literacy," Prof. Trollor says.

The researchers say preventable hospitalisations, higher multi-morbidity, and over-representation of premature and potentially avoidable deaths are just the tip of the iceberg which underly a major gap in healthcare.

Lived experience

Jack Kelly, a person with lived experience of intellectual disability and Project Worker at Council for Intellectual Disability, says some health professionals just don't get it. "They can work with people without a disability well but for people with a disability they don't know where to turn. What we need is increased training for health staff in supporting people with an intellectual disability, and longer appointments time so the person with an intellectual disability has more time to say what they want to say without feeling rushed."

For many years, the Council for Intellectual Disability has been advocating for fundamental action by governments on the health of people with intellectual disability. The Council's Senior Advocate Jim Simpson said: "Here, we have yet more rigorous evidence of the stark health inequalities suffered by people with intellectual disability. We

have welcomed initiatives by Health Minister Greg Hunt including the development of a National Roadmap for Improving the Health of People with Intellectual Disability. We now look to the Minister to release and implement the Roadmap as a matter of urgency."

More information: Janelle C Weise et al, Potentially preventable hospitalisations of people with intellectual disability in New South Wales, *Medical Journal of Australia* (2021). [DOI: 10.5694/mja2.51088](https://doi.org/10.5694/mja2.51088)

Provided by University of New South Wales

Citation: People with intellectual disability at 'unacceptably high' risk of preventable hospitalization (2021, June 14) retrieved 11 May 2024 from <https://medicalxpress.com/news/2021-06-people-intellectual-disability-unacceptably-high.html>

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