

Preventing Suicide in People with Intellectual Disabilities

CHANGING THE NARRATIVE ON SUICIDE



Background

An intellectual disability is a neurodevelopmental condition that begins in childhood and affects intellectual functioning (usually characterised by a standardised IQ score below 70) and adaptive behaviour. Intellectual disabilities are often classified by severity levels based on the level of support the person needs, ranging from mild (typically an IQ of around 50–70, known as borderline intellectual functioning), to profound. Mild intellectual disabilities (borderline intellectual functioning) are the most common, yet the most likely to go unrecognised or unrecorded. This has direct consequences for the self-harm and suicide data.

People with intellectual disabilities die around 20 years earlier than the general population. This is not an inevitable consequence of having an intellectual disability: systemic barriers to accessing support, structural ableism, and diagnostic overshadowing are associated with poor health outcomes and avoidable deaths. As a result, many people do not receive appropriate assessment, treatment or support. Interventions are often not sufficiently adapted to how a person communicates, processes information or experiences emotions, which makes treatment less effective. To change this, joined-up working is required across health, mental health, social care and education, in collaboration with the person themselves and those who know them well.

Scientific research has systematically excluded people with intellectual disabilities. Many clinical trials and epidemiological studies have left people out due to assumptions about capacity, inaccessible research design, eligibility criteria that screen people out, and a lack of researcher training and awareness of intellectual disability.

Though there has been a shift towards coproduced work alongside those with intellectual disabilities to address their exclusion from research, suicide prevention has a long way to go. People with intellectual disabilities are disproportionately exposed to known risk factors for suicide, such as serious mental illness, isolation, stigma and discrimination, self-harm, and psychiatric hospitalisation.

Key Points

People with intellectual disabilities are not one single group. Their lives, support needs and ways of expressing distress vary hugely and research can sometimes pool people together in a way that hides some of these differences.

Different countries define and identify intellectual disabilities differently, so studies are not always looking at the same population.

People with intellectual disabilities are more likely to experience physical and mental health problems and are often not given access to ways to express or make sense of their distress. Distress that isn't recognised or understood is less likely to be captured in statistics.

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Professional support is generally considered protective from suicidality, but it can introduce risks of its own: discontinuities in care, support that is not sensitive or responsive to the person, and in some settings exposure to the distress of other people, which can present challenging group dynamics. Yet very little is known about how suicide affects people with intellectual disabilities, or how people themselves experience suicidality.

Assumptions about intent, level of understanding, and abstract thinking ability can mean expressions of suicidal feelings are interpreted behaviourally rather than through the lens of suicidal distress. There are few validated screening measures or risk assessment tools in people with intellectual disabilities, and much of the current work in this field relies heavily on the perceptions of others (caregivers, clinicians) rather than centring the voices of people with intellectual disabilities themselves. Furthermore, evidence-based treatment and adapted support for people with intellectual disabilities who experience suicidality is scarce. Resources that may be available for people without intellectual disabilities have not been validated in this population, so things like crisis helplines, mental health apps and safety planning might not be accessible or helpful to people.

Call to Action

Researchers and funders: Urgent action is needed to address the exclusion of people with intellectual disabilities from suicide prevention research. Collaboration with those with lived experience is essential to ensure we understand how suicide affects people. Tools, resources, support and academic work should be coproduced using Easy Read, adapted language, storytelling and creative and ethnographic methods to capture people's views and experiences. We must get better at listening to people with intellectual disabilities.

Services and professionals: Ensure expressions of distress are taken seriously, and effort is made to adapt communication to reveal the drivers of suicidal behaviour. Understand the circumstances and context of the distress, avoiding dismissal through assumptions about how much people with intellectual disabilities can understand or feel.

People with intellectual disabilities and families should be provided with accessible and validated crisis support and resources; such resources should be coproduced to be fit for purpose.

Facts & Figures

People with intellectual disabilities are over three times more likely to engage in self-harm than the general population

Some estimates suggest lower recorded risk of suicide in people with intellectual disabilities — around 46% lower than the general population. Other estimates suggest that people with intellectual disabilities are at higher risk of suicide.

Recorded suicide risk is determined by the level of support needs and adaptive skills, with more severe intellectual disabilities associated with a lower risk of suicide. However, as many estimates of suicide rates pool data across levels of intellectual disability, and mild intellectual disabilities are often unrecorded, these estimates might not be accurate



Resources

- <https://prevent-suicide.org.uk/find-help-now/stay-safe/>
- <https://cid.org.au/resource/my-safety-plan/>
- Practical guidance can be found [here](#) on how caregivers and professionals might talk with a person with intellectual disabilities about suicide.
- Information about how suicide safety plans can be adapted for young people with intellectual disabilities can be found [here](#).

Useful References

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