

A Research Summary

Avoidable deaths in adults with intellectual
and developmental disabilities including
Down syndrome in Ontario



Learn more about the research paper [here](#)



Trigger warning: death and dying

Why did we do this research?

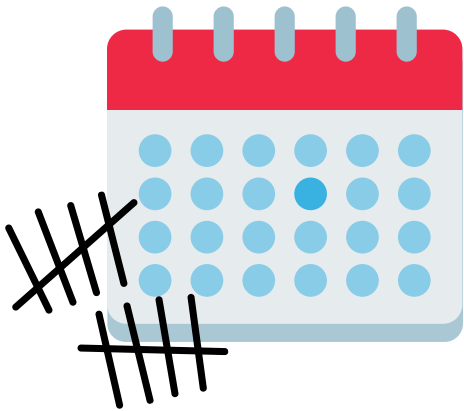
To learn if more adults with intellectual and developmental disabilities (IDD) die of things that can be avoided compared to people without IDD.



To learn if this was the same for adults with Down syndrome.



What did we do?



We **counted adults** with **IDD** aged 65 and younger in Ontario who died between 2010 and 2016.



We also looked at adults that had Down syndrome and adults that did not.

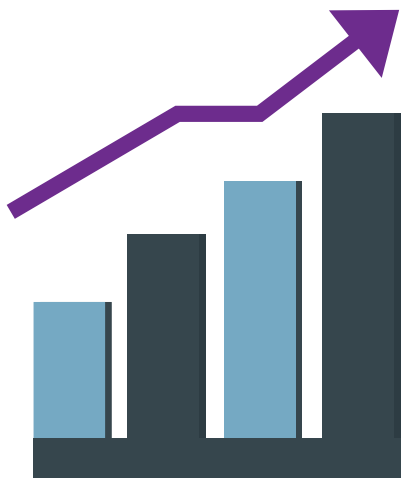


We compared adults with IDD to adults without IDD.



Of the people we looked at who died, we wanted to know which deaths could have been **prevented** with the **right medical care** (this is called an "amenable death").

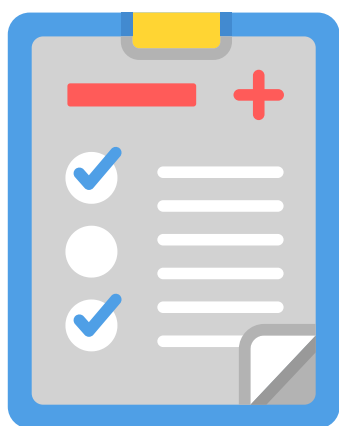
What did we learn?



Adults with IDD were more likely to die than other people. This was a big problem for people with Down syndrome.



People with IDD (with and without Down syndrome) were also more likely to die from health problems that **could have been stopped** or slowed down.



Many things can explain why these deaths happen, like being older or having health problems. But we need to know more about **why people died.**

What does this mean?



Better health care could prevent some deaths from happening.

It is not enough to know that people die earlier than they should.

People are dying when they could have had help earlier so they would not die. We need to help people with IDD get the care they need when they need it.



This summary is about a research article: [**Amenable deaths among adults with intellectual and developmental disabilities including Down syndrome: An Ontario population-based cohort study**](#), published in the Journal of Applied Research in Intellectual Disabilities in November 2022.

This guide was created by staff at the Health Care Access Research and Developmental Disabilities Program (H-CARDD) and CAMH.

We thank the self-advocate advisors who worked together with our team.

camh | Azrieli Adult
Neurodevelopmental Centre

 made with
photosymbols®



Health Care Access Research
and Developmental Disabilities

and

Canva