

Promoting Brain Health, Facing Our Fears, and Caring for One Another

By Yona Lunsky

March is [Brain Health Awareness Month](#), and this week is Brain Awareness Week, so it is fitting that we are launching the third cycle of our [Brain Health-IDD program](#). This program brings together people with intellectual and developmental disabilities (IDD), family caregivers, and service providers in the health and disability sectors from across Canada. Our goal? To teach about brain health and healthy aging, reduce the risk of dementia in our community, and encourage proactive screening. (You can read more about the program [in this blog post](#).)

This is still a relatively new area for me, and I'm learning just as much as the people taking the courses—why brain health matters so much, and why we need to pay closer attention.

A few weeks ago, my colleagues from Ontario Tech University and ICES published one of the first population-based studies on the incidence and prevalence of dementia in people with IDD, both with and without Down syndrome. (You can [read the study here](#)).

What did the researchers do?

Building on our H-CARDD work, the study authors created a cohort of adults with IDD for each year in the 10-year study period. At the start of the study, none of these individuals had a dementia diagnosis recorded in their health records, nor did the adults without IDD they were compared to. The researchers examined the incidence (number of new diagnoses each year) in three groups: people without IDD, people with Down syndrome, and people with IDD not including Down syndrome. They also looked at the overall prevalence (number of people with dementia, both new and existing cases) each year and at the end of the study.

What did they find?

The study found that people with IDD are much more likely to develop dementia compared to those without IDD. Specifically, for people with IDD (excluding Down syndrome), the risk of developing dementia was more than four times higher than

in the general population. For people with Down syndrome, the risk was over five times higher.

Not only were new cases diagnosed at a much higher rate, but the total number of people living with dementia at any given time was also significantly greater in both groups. Importantly, the age of diagnosis was younger for people with IDD, not just for those with Down syndrome.

What does this mean?

As the authors note in their paper, our provincial and national policies need to recognize these higher rates of dementia and ensure that dementia supports and services are accessible and can accommodate people with IDD. This also means that providers in both the disability and dementia sectors need training to provide appropriate care.

But it is not enough to just diagnose and treat dementia. We have to think about brain health more broadly. That means promoting positive brain health as people with IDD age, and focusing on [“modifiable risks”](#), i.e. the things we actually can do something about.

Dementia is a reality for many of us, and the risk is even greater for our population. But when symptoms begin, how quickly they progress, and how much someone enjoys life with dementia—these are things we can have some control over. As they say on [Defy Dementia](#), my favourite podcast on this topic, *“you’re never too young or too old to take care of your brain.”* (Speaking of Defy Dementia, keep an eye out for a special episode later this month on brain health for people with IDD and their family caregivers—just in time for World Down Syndrome Day!)

Facing Our Fears and Taking Action

Through our brain health program, I’ve come to realize how hard it is to care about and act on something that isn’t even on our radar. This becomes even harder when fear takes over. We have faced some challenges recruiting for our Brain Health-IDD courses, partly because many people are unfamiliar with brain health and partly because the topic itself stirs up some deep fears.

These challenges have reminded me of two things we need to work on together.

1. **We need to build awareness about dementia so we can take collective action—understanding what it is and why it matters.** People need facts and guidance, and that starts with ensuring people with IDD are included in dementia research. We must also work together with our communities to translate research into accessible information so everyone can understand it.
2. **We need to help people face their fears about this very difficult and scary topic, gently and with kindness.** Fear can be paralyzing, making it hard to take action. In these moments, people need support, reassurance, and direction. What is one small step that can be taken? How can we help people feel less frightened and alone to take that first step? Who can help? We have seen that with support, people can face what they fear more easily.

By supporting one another, and taking action, we can make a real difference in brain health, healthy aging, and dementia care for people with IDD.

Want to learn more about our Brain Health-IDD program?

Upcoming courses:

Adults with IDD – please [click here](#) for more information

Date and Time: Every Tuesday, March 25 to May 6, 2025 from 1:30-3:00pm EDT

Service Providers – please [click here](#) for more information

Date and Time: Every Friday, May 2 to June 6, 2025 from 11:30am-1:00pm EDT

Family Caregivers - please [click here](#) for more information

Course offered in two formats:

1. Offline, video recordings (Spring sign up)
2. Online, at a scheduled time (Fall 2025)

Registration link: <https://redcap.link/9uja13v6>

Email: brainhealthIDD@camh.ca