

From Pregnancy to Aging: Supporting Caregiving Across the Lifespan in the Disability Community

By Yona Lunsky

The end of May marks the end of National Caregiver Month in Canada, featuring the [Caregiver Aware](#) campaign. This month also saw the release of a [powerful report on caregivers](#) from the [Canadian Centre for Caregiving Excellence \(CCCE\)](#).

I have been reflecting a lot on caregiving this month at both the start and late in life. I have been working closely with family caregivers on our [Brain Health-IDD Program](#) – educating care providers about aging family caregivers, and educating aging family caregivers about their own brain health and that of their family members with disabilities. Perhaps the most important lesson I have learned is that the roles of caregivers and care recipients when it comes to people with disabilities are not as straightforward as one might think. In our teaching about brain health and dementia, we are realizing that people with developmental disabilities are just as likely to be caregivers for their parents, partners, or roommates as they are to need care themselves. In that same vein, older family caregivers can also find themselves after many years of caregiving in the role of patient or care recipient.

This complexity is also evident at the start of life. Supporting new parents of children with developmental disabilities and disabilities more generally is crucial; however, it is equally important to remember that new parents themselves can have disabilities. Earlier this week, we released a [landmark study on pregnancy and disability](#), highlighting the health inequities experienced by pregnant individuals with sensory, physical and developmental disabilities and offering solutions. This report, led by my colleague Hilary Brown, examined over 150,000 pregnancies of disabled people in Ontario, and combined this rich dataset with 60 qualitative interviews with parents, service providers and policymakers.



Whether we are focusing on care at the start or in late life, we have to remember that disabled people need support to help them be the best caregivers they can be. I use the term “disabled” here because what can make caregiving challenging is not the disability itself, but the lack of accommodations available to people with disabilities. Indeed, we disable people by not providing them with the support they need on their caregiving journey.

We began the month of May with the release of the CCCE Caregiver Report, and ended it with [National AccessAbility Week](#) and our pregnancy and disability report. This week, we take time to celebrate our achievements in making care and life more accessible while also recognizing that so much more work needs to be done.

As I reflect on these successes and challenges, one other important lesson stands out. The pregnancy and disability project, which has been ongoing for seven years, highlighted key similarities across disabilities and identified new allies to me who were interested in inclusive practices and the unique issues related to different disabilities. While some of our work focuses on specific communities, such as people with developmental disabilities with unique needs, **I have learned that broader innovations and impacts often come from cross-disability partnerships.** This lesson is echoed in our new work on brain health and IDD, where there is much common ground and mutual learning with our dementia partners. There are ways to continue studying and highlighting unique issues related to developmental disabilities while also being part of something bigger.

Collaborating with people with lived experience is key. “Nothing About Us Without Us” is a principle that guides what we do. The success of the two programs I have been focused on this month is built on a foundation of trust and collaboration. People with disabilities and caregivers of all abilities are vital members of our research teams. Studies involving the full disability community are essential, and we must continue to work closely with both people with disabilities and caregivers, including disabled caregivers, on all projects to ensure our programs are meaningful and relevant.

Resources

- Read our report on pregnancy and disability, [Equity and inclusion in pregnancy care: report on the pregnancy outcomes and health care experiences of people](#)



[with disabilities in Ontario](#). On this page, you can also find an Easy Read version developed with advisors from the H-CARDD program.

- Read a [commentary on the pregnancy and disability report](#), written by members of our team.
- Our pregnancy and disability report in the news: Global News, [Pregnant people with disabilities face barriers to accessible care: report](#)
- Read the report on Caring in Canada from CCCE, [Caring in Canada: Survey insights from caregivers and care providers across Canada](#)
- [Learn more about our Brain Health-IDD Program](#).