

## From Atlas to Action: A Reflection on the Past 10 Years of the Health Care Access Research and Developmental Disabilities Program (H-CARDD)

By Yona Lunsky

As we approach the holiday season, I am reminded that it has been 10 years since the release of the H-CARDD [Atlas on the Primary Care of Adults with Developmental Disabilities in Ontario](#). This Atlas provided, for the first time in Canada, descriptive information on the health of over 66,000 adults with developmental disabilities in Ontario. It examined the quality of their primary care relative to adults without developmental disabilities, revealing disparities in preventive care and chronic disease management. The Atlas concluded with a call to action, urging changes for a group whose health care needs had been invisible for far too long.

Atlas on the Primary Care  
of Adults with Developmental  
Disabilities in Ontario

December 2013



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Ten years ago also marked the beginning of our exploration into new ways to share information beyond the research community. Alongside our full report and executive summary, we posted a series of [H-CARDD Snapshots](#) highlighting key findings from each chapter of the Atlas. We now have over two dozen Snapshots based on many different projects and research papers. We also created a [video summarizing what we learned](#) from the study, in a format accessible to adults with developmental disabilities and their families. This is because we recognize that not everyone learns through reading alone; sometimes watching or talking about something is an easier way to understand information. We continue to explore different ways to share information, including [videos](#), a [podcast](#) and [Easy Read summaries](#) of our work.

When I think about our journey over the last decade, I am keenly aware that many aspects of health care remain quite problematic. But there is one important difference. Over the past 10 years, we have been actively counting, and that makes people with developmental disabilities visible when it comes to making health care accessible.

Following publication of the Atlas, members of the H-CARDD team branched out to focus on many emerging issues, documenting problems and trialing different interventions. Projects covered topics such as [aging](#), [women's health](#), [transitioning into adulthood](#), and the ["dual diagnosis" of disability and mental illness or addiction](#). At the same time, research was carried out evaluating the [implementation of health checks](#) and health care improvements in [family health teams](#) and [hospital emergency departments](#). Lessons learned from these projects were summarized in our 2016 report, [Making the Invisible Visible](#).

In 2019, we published [a follow-up ICES report](#) examining problematic health care outcomes over a six year period, using the same cohort as our original Primary Care Atlas. This study found that adults with developmental disabilities did worse across five key health care outcomes when compared to other adults.

Shortly thereafter, team members tackled the [intersection of developmental disability with the criminal justice and forensic mental health systems](#), looking at provincial and federal corrections, as well as inpatient and outpatient forensic mental health care. We also focused on the development of [patient-oriented health care communication tools](#), as well as evidence-informed guidance on health care practices. Working together with people with disabilities, families, and community staff, we created [new tools and toolkits for community agencies and family caregivers](#). Most recently, [we published guidance](#) designed to support the successful transition of patients with a dual diagnosis from hospitals to community settings in Ontario.

While the pandemic temporarily slowed some of the H-CARDD Program’s work it also led to important discoveries and collaborations. For the first time in Canada, team members documented the [impacts of COVID-19 on the developmental disability population](#). We collaborated with groups across Canada to leverage this knowledge, [advocating for more accessible vaccinations](#) and [supporting the mental and physical health of this population and those who care for them](#).

Our 2013 Atlas concluded with three recommendations: (1) improve the quality of primary care based on best evidence and care standards; (2) modify broader health care system structures and processes; and (3) strengthen partnerships with patients, their families and their paid caregivers. Ten years later, the Canadian Developmental Disabilities Primary Care Program has published a number of evidence-informed [primary care practice tools](#), along with updated [health care guidelines](#). As well, a [new fee code specific to the IDD Health Check](#) was added to the OHIP Schedule of Benefits in April 2023.

While progress has been made in each of these areas, there is still so much work to be done here in Ontario and across the country. It begins with counting but it doesn’t end there. We

**People with developmental disabilities fare worse in the health system across multiple indicators** IC/ES

Report from ICES finds that Ontario adults with developmental disabilities experience worse health outcomes, regardless of age, sex, neighbourhood income or type of developmental disability. For most indicators, these outcomes are more likely with age.

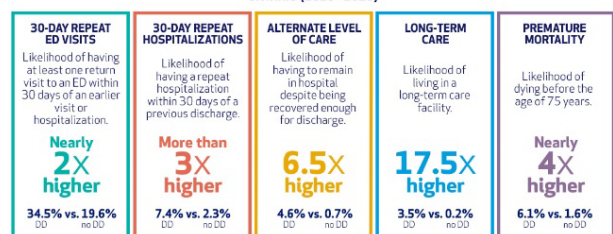


The researchers looked at health records for nearly 65,000 Ontarian adults under the age of 65 with developmental disabilities such as Down syndrome or autism. They looked at the records over a six year period (2010-2016) and compared them to Ontarians who don't have these disabilities.

**“I would like doctors to have a little more time for people with disabilities, and be more understanding. We’re a little slower than other people are. We need more time to talk to them.”**

— Michael, self-advocate

**HIGHER RATES OF POOR HEALTH OUTCOMES FOR ADULTS WITH DEVELOPMENTAL DISABILITIES COMPARED TO ADULTS WITH NO DEVELOPMENTAL DISABILITIES**  
 ONTARIO (2010 - 2016)



Lin E et al. Addressing Gaps in the Health Care Services Used by Adults with Developmental Disabilities in Ontario. ICES, 2019.



have to continue counting to ensure no one is overlooked and we have to act based on what we learn. Together, we need to blend numbers with stories and build strong partnerships between scientists, clinicians, policy makers and people with lived experience.

If you are not familiar with the H-CARDD program, please check out our [newly updated website](#) to learn about our [work from the past ten years](#). If you are familiar with H-CARDD and have been a part of our work, thank you for partnering with us and showing that people with developmental disabilities and their families count when it comes to their health.

We always enjoy hearing from you. [Share what you have learned over these past ten years](#), and more importantly, tell us what you think should be prioritized in the next ten years when it comes to health care and developmental disabilities.