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

## Summary

November 2013



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## SUMMARY

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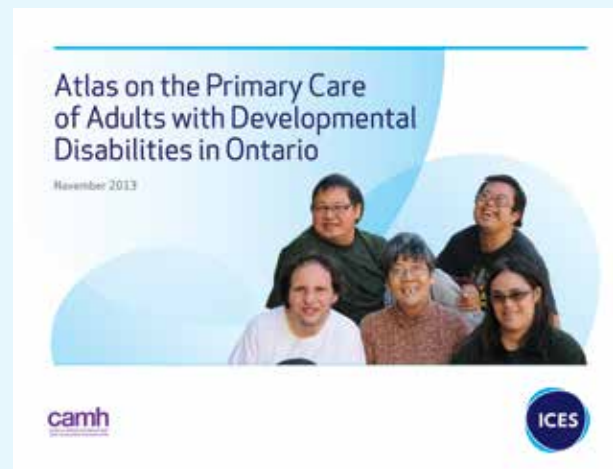
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The opinions, results and conclusions reported in this study are those of the authors and are independent from the funding sources. No endorsement by the Institute for Clinical Evaluative Sciences, the Centre for Addiction and Mental Health, the Ontario Ministry of Community and Social Services or the Ontario Ministry of Health and Long-Term Care is intended or should be inferred.



The full report will be available at [www.ices.on.ca](http://www.ices.on.ca), [www.knowledgex.camh.net](http://www.knowledgex.camh.net) and [www.hcardd.ca](http://www.hcardd.ca) in December 2013.

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## About the Atlas

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The Atlas is an initiative of the Health Care Access Research and Developmental Disabilities (H-CARDD) Program. It provides, for the first time in Canada, descriptive information on the health of adults with developmental disabilities in Ontario and examines the quality of their primary care relative to adults without developmental disabilities. These findings will also have relevance in other jurisdictions where there is interest in improving health care and the health status of those with developmental disabilities.

The Atlas has three main goals:

1. To provide prevalence estimates, demographic information and a description of the health status of adults with developmental disabilities in Ontario.
2. To examine their health care use relative to other adult Ontarians.
3. To assess how consistent their care is with primary care guidelines.

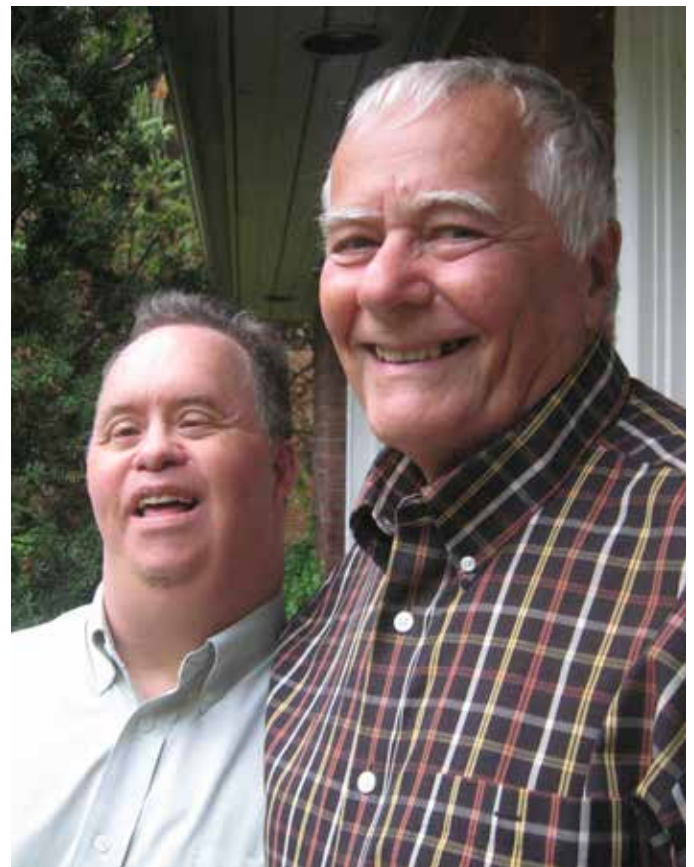
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## Key Findings

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### Prevalence, Demographic and Disease Profiles

- Through linked data from Ontario's social services and health sectors, the total number of adults between the ages of 18 and 64 years coded as having developmental disabilities between April 2009 and March 2010 was 66,484. This corresponds to a prevalence of 0.78%, an estimate that is somewhat higher than reported in previous work relying on fewer data sources.
- Compared to the population of adults without developmental disabilities, adults with developmental disabilities were younger and a greater proportion were male. They were more likely to live in poorer neighbourhoods and in rural areas. They also had higher rates of morbidity and were more likely to be diagnosed with a range of chronic diseases.



## Health Services Utilization

- Despite comparable use of family physicians and similarities in continuity of care, adults with developmental disabilities were more likely to visit emergency departments and to be hospitalized. For adults with developmental disabilities, being older or having high morbidity increased the likelihood of visiting the hospital above what would be expected for adults without developmental disabilities.
- Most adults with developmental disabilities were seeing physicians practicing in a primary care enrolment model. Although interprofessional care is recommended for this population, only 20% were receiving their care through interprofessional Family Health Teams.

## Secondary Prevention

- Having a periodic health examination, a key health care guideline for adults with developmental disabilities, occurred for 22% of the H-CARDD cohort, slightly less than the 26% for adults without developmental disabilities. The likelihood of this examination increased with neighbourhood income level for both groups.
- Adults with developmental disabilities were less likely to undergo recommended screening for the three types of cancer studied. Income level did not affect cancer screening rates for adults with developmental disabilities, although it did affect the uptake among those without developmental disabilities. The low preventive care rates for adults with developmental disabilities were consistent for all regions of Ontario.

## Chronic Disease Management

- The rate of eye examinations among persons with diabetes was higher for adults with developmental disabilities than those without (63% versus 57%). The rate of follow-up with a family physician or psychiatrist within 30 days of a psychiatric emergency department visit was the same for adults with and without developmental disabilities (58%).

“As parents, we went through a feeling of utter helplessness. The hospital system tried to do its best, but we were offered only band-aid solutions. Although the level of care was good during emergencies, there was a recurring mantra of ‘patch her up and send her out until the next time.’ We really hoped for a lasting solution outside of initial crisis intervention. We found doctors to be hard-pressed for time to provide a course of action for family caregivers beyond intervention, and they ultimately left it to us to find a solution on our own. We felt then, as we do now, that there needs to be a better process that connects hospitals, caregivers, family doctors and patients with a focus on long-term intervention, thereby reducing the need for emergency hospitalization.”

- Disparities were observed for osteoporosis monitoring and preventable hospitalizations. The proportion of adults with developmental disabilities who received bone mineral density testing within one year of experiencing a low-trauma fracture was 14% compared to 20% among adults without developmental disabilities. Similarly, the rate of preventable hospitalizations for those with developmental disabilities was much higher across age groups and neighbourhood income levels.

## Medication Use

- Nearly one in two adults with developmental disabilities were dispensed multiple medications at one time, with 22% being dispensed five or more medications concurrently. The most commonly prescribed medications were for mental health or behavioural issues, with antipsychotic medications prescribed most frequently. Older persons with developmental disabilities, women and those with high levels of morbidity were more likely to be dispensed multiple medications, while income level and urban/rural residence showed no impact.
- Approximately one in five adults prescribed anti-psychotics were dispensed the dangerous combination of two antipsychotics concurrently, putting them at risk for adverse reactions, which can include death. Regular follow-up visits with the same family physician did not take place for 32% of persons dispensed five or more medications at once.

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## Conclusions

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The Atlas reveals many gaps in the care of adults with developmental disabilities that need to be addressed if Ontario is to meet the standards set out in the *Excellent Care for All Act*. While primary care providers are pivotal to achieving needed changes, the broader health care context that supports primary care provision also needs to be considered. We propose changes in three areas:

1. **Improving quality of primary care based on best evidence and care standards.** This includes a balanced emphasis on mental and physical health issues and on the prevention and management of disease. Care requires an interprofessional approach with an emphasis on embedding guidelines and clinical tools into daily practice.
2. **Modifying broader health care system structures and processes.** This includes focusing on the development and maintenance of care plans, fostering collaboration and coordination across the health system, the inclusion of other relevant sectors, and an emphasis on financial structures required to support collaborative care.
3. **Strengthening partnerships with patients, their families and their paid caregivers.** To improve accessibility and quality of care, it is essential that the patient be at the centre of care and that those involved in supporting the individual, whether paid or unpaid, be recognized for the vital role they play.

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## Next Steps

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Future research needs to expand beyond primary care to the broader health care system and should focus on those critical subgroups that experience the most significant difficulties in receiving optimal care. The Atlas provides an important starting point from which to identify gaps in primary care and approaches for addressing them. At the core of this future research will be the collaborative cross-sectoral relationships developed through this project.



## About the Organizations

### About H-CARDD

Health Care Access Research and Developmental Disabilities (H-CARDD) is a research program whose primary goal is to enhance the overall health and well-being of people with developmental disabilities through improved health care policy and services. H-CARDD research is conducted by dedicated teams of scientists, policy-makers, and health care providers, working collaboratively under the direction of Dr. Yona Lunsky.

The H-CARDD research program was developed to address the disparities in health status and health care access faced by people with developmental disabilities. The complex health care needs of people with developmental disabilities are frequently met with difficulties in accessing appropriate services and health care providers with little knowledge of how best to serve them. To address these issues, H-CARDD is focused on enhancing the capacity of decision-makers to develop policy and monitor system performance and on using research to enable service providers to offer high-quality health care services.

H-CARDD's partners in the creation of this Atlas include the Ontario Ministry of Community and Social Services, the Ontario Ministry of Health and Long-Term Care, Surrey Place Centre, the University of Ontario Institute of Technology, the University of Ottawa and Queen's University, as well as ICES and CAMH. H-CARDD was funded for this work by the Partnerships for Health System Improvement program of the Canadian Institutes of Health Research.

### About CAMH

The Centre for Addiction and Mental Health (CAMH) is Canada's largest mental health and addiction teaching hospital, as well as one of the world's leading research centres in the area of addiction and mental health. CAMH combines clinical care, research, education, policy development and health promotion to help transform the lives of people affected by mental health and addiction issues.

CAMH is fully affiliated with the University of Toronto and is a World Health Organization/Pan American Health Organization Collaborating Centre in Addiction and Mental Health.

### About ICES

Since its inception in 1992, the Institute for Clinical Evaluative Sciences (ICES) has played an important role in providing unique scientific insights to help policy-makers, planners and practitioners shape the direction of Ontario's health care system.

Key to our work is our ability to link population-based health information, at the patient level, in a way that ensures the privacy and confidentiality of personal health information.

ICES receives core funding from the Ontario Ministry of Health and Long-Term Care. In addition, our scientists compete for peer-reviewed grants from federal funding agencies, such as the Canadian Institutes of Health Research, and receive project-specific funding from provincial and national organizations. The knowledge that arises from our research is always produced independent of our funding bodies, which is critical to our success as Ontario's objective, credible source of evidence guiding health care.

