



Health Care Access Research
and Developmental Disabilities

HEALTH CARE ACCESS RESEARCH AND
DEVELOPMENTAL DISABILITIES (H-CARDD)

March 2016



Summary of Proceedings: 'Making the Invisible Visible'
H-CARDD Provincial Meeting, February 23, 2016

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Agenda

‘Making the Invisible Visible’

Provincial Meeting for Health Care Access Research and Developmental Disabilities

February 23, 2016

8:45am-12:30pm, followed by lunch
Location: 20 Grosvenor Street, Toronto
Auditorium - YMCA

- Objectives:**
- To share H-CARDD findings and lessons learned
 - To engage in discussion on how the H-CARDD findings can support short and long term changes in policy and in practice

Agenda

8:15 – 8:45 *Breakfast*

8:45 – 9:15 **Welcome and Introductions**

Yona Lunsky, H-CARDD Director

Janet Menard, Deputy Minister, Ministry of Community and Social Services

Rae Roebuck, Facilitator

9:15 – 10:00 **Data Discoveries**

Introduction: Yona Lunsky

- 1. Women’s Health:** Simone Vigod
- 2. Youth and Young Adults:** Barry Isaacs
- 3. Mental Health and Addictions:** Elizabeth Lin
- 4. Aging Project:** Lynn Martin
- 5. Emergency Care Implementation Project:** Jacques Lee
- 6. Primary Care Implementation Project:** Ian Casson

Summary: Rob Balogh

10:00 – 10:40 **Changing the Trajectory**

Introduction: Yona Lunsky

- **Transitions from Child to Adult Care:** Jonathan Weiss
- **Accessing Services Related to Aging:** H el ene Ouellette-Kuntz
- **Navigating Complex Health Care Situations:** Yona Lunsky

Summary: Janet Durbin

10:40 – 10:50 *Break*

10:50 – 12:10 **Possibilities for Action**

Introduction: Rae Roebuck

Summary: Heather Bullock and Rae Roebuck

12:10 – 12:30 **Closing Remarks**

Nancy Naylor, Associate Deputy Minister, Ministry of Health and Long-Term Care

12:30 – 1:00 *Lunch*

'Making the Invisible Visible' H-CARDD Provincial Meeting February 23, 2016

Main Messages

- H-CARDD is a research program with the primary goal of enhancing the overall health and well-being of individuals with developmental disabilities through improved health care policy and services in Ontario.
- On February 23rd, 2016, an intersectoral provincial meeting called 'Making the Invisible Visible' was hosted by H-CARDD and attended by researchers, policymakers, service planners and providers, and representatives from advocacy organizations to focus on health and health care access for adults with developmental disabilities.
- Over the past 3 years, the H-CARDD program has conducted 6 research projects:
 - Four projects focused on vulnerable subgroups (transition age youth and young adults, women, older adults, adults with mental illness and addictions); and,
 - Two implementation projects focused on primary and emergency care.
- Together, these projects demonstrate the benefits of working with different data sources and collaborating with policymakers, service providers, and adults with developmental disabilities and their caregivers in order to understand and address health care challenges.
- Through these projects, H-CARDD researchers identified 3 critical time points when there are opportunities to improve the health care trajectories of this population:
 1. when youth and young adults transition into adult services;
 2. when adults begin accessing services related to aging; and,
 3. any time in adulthood when complex health conditions lead to hospital use.
- Several patient/individual and system level opportunities were identified amongst the 86 attendees in 10 small group discussions. These opportunities focused on:
 - investing in and utilizing data at the individual and system level;
 - individualizing clinical care with common tools across settings;
 - improving service access, coordination and navigation;
 - fostering cross-sector relationships;
 - taking a lifespan approach to proactive care and health promotion; and,
 - promoting education of health care professionals, patients, and caregivers about developmental disabilities.

Introduction

On February 23rd, 2016, the ‘Making the Invisible Visible’ provincial meeting hosted by H-CARDD brought together diverse policy and practice stakeholders from across Ontario sectors to:

1. reflect on the data discoveries from our research;
2. highlight opportunities for changing the health and health service trajectories of adults with developmental disabilities; and,
3. develop strategic actions for policy and practice.

Eighty-six individuals were in attendance, including clinicians, health planners from different LHINs, executive directors, representatives of community, social, health care and advocacy organizations, and policymakers from five provincial ministries (i.e., MCSS, MOHLTC, EDU, MCYS, and MAG).

The day focused on findings about the health and health service use of adults with developmental disabilities from a 3-year program of research conducted by H-CARDD through a grant from the MOHLTC Health System Research Fund (2013-2016). Opening remarks were made by Janet Menard, Deputy Minister, MCSS, and closing remarks by Nancy Naylor, Associate Deputy Minister, MOHLTC. Both leaders emphasized the importance of an intersectoral approach to health and health care for this population, and the value of integrating research with policy and practice.

Background

Adults with developmental disabilities have higher rates of preventable diseases and conditions (e.g., chronic disease and mental illness), and often have complex health care needs. Yet, they face greater challenges in accessing appropriate primary care and other health services, and tend to encounter health care providers with little knowledge of how to support them. Their complex health needs often ‘fly under the radar’ in broader policies and initiatives.

H-CARDD research draws attention to the complex health care needs of this population and to innovative approaches to improving care through research, and integrated knowledge translation and exchange. From the start, H-CARDD has partnered with a range of stakeholders and knowledge users to share and interpret research findings and to discuss how to use these findings to inform policy and practice. Knowledge users have included adults with developmental disabilities, families/paid caregivers, health care providers and planners (e.g., from the LHINs), developmental service providers and planners, and policy stakeholders, including representatives from four provincial ministries (MOHLTC, MCSS, MCYS, and EDU).

In previous research, H-CARDD identified a cohort of approximately 66,500 adults between the ages of 18 to 64 years as having developmental disabilities in Ontario by linking social service and administrative health data and published a report about their health and health service use called the *Atlas on the Primary Care of Adults with Developmental Disabilities in Ontario*.

Building on this work, **6 research projects** were carried out between 2013 and 2016 to **achieve two objectives**:

1. **Knowledge Creation** – To examine the health and health service needs of 4 vulnerable subgroups (transition age youth and young adults, women, older adults, adults with mental illness and/or addictions); and,
2. **Knowledge-to-Action** - To evaluate the implementation of new practices and clinical tools in 2 health care settings (primary care and emergency care).

Data Discoveries

Following introductory comments, the first part of the morning focused on data discoveries. An important step toward ‘making the invisible visible’ is using data to draw our attention to the health and service use of adults with developmental disabilities. The 6 project teams presented their findings and discussed how these findings served to confirm prior anecdotal reports in different topic areas, but also provided examples of new and sometimes unexpected findings. Key findings from the research projects are summarized on 6 H-CARDD Snapshots (see appendix). Highlights from the **Knowledge Creation** projects include:

1. **Transition age youth and young adults** are more likely to have poorer overall health, have at least one psychiatric diagnosis, see a physician or psychiatrist, and go to the emergency department or be hospitalized compared to those without developmental disabilities (speaker: Dr. Barry Isaacs).
2. **Women** are at a higher risk for pregnancy-related medical problems, and less likely to be screened for breast and cervical cancer than women without disabilities. Women and men may have different levels of side effects from antipsychotic medication. For example, women may be at higher risk of blood clots than men (speaker: Dr. Simone Vigod).
3. **Older adults** experience higher rates of frailty and use aging care services more often and at much earlier ages than the general population. As early as 50 years of age, adults with developmental disabilities show levels of frailty comparable to adults without developmental disabilities 80+ years (speaker: Dr. Lynn Martin).
4. **Adults with mental illness and addictions** have a higher prevalence of serious health issues compared to other adults. They are also more likely to have repeat visits to hospital and emergency departments, and stay in hospital longer than necessary. Nearly 1 in 2 adults with developmental disabilities have a psychiatric diagnosis, and 12% of these individuals have an addiction (speaker: Dr. Elizabeth Lin).

Highlights from the **Knowledge-to-Action** projects include:

1. **Primary Care:** Proactive processes to identify patients with developmental disabilities and invite them for ‘health checks’ were successfully implemented in two primary care settings. Patients who received health checks had more preventative care than those who did not,

but may require longer visits. Electronic medical record (EMR) based clinical tools and training can help staff adapt their care practices (speaker: Dr. Ian Casson).

2. **Emergency Care:** Increasing staff comfort and skills to identify patients with confirmed or suspected developmental disabilities is key to improving the quality of emergency care. Education can help staff become more familiar and at ease with these patients and in using available clinical tools to help with communication. Getting staff to use these tools takes time (speaker: Dr. Jacques Lee).

Fitting implementation into local priorities and having champions on site were key to more successful outcomes in both projects.

Summary of Data Discoveries

Together, the 6 projects took advantage of administrative data, qualitative interview data, survey data, and chart audit information to learn more about health care and developmental disabilities. In a summary presentation on the benefits of existing data and ongoing data needs, Dr. Balogh highlighted the necessity of using multiple data sources, and the benefits of linking data from across sectors, in order to better represent the health and health service use of the entire population with developmental disabilities. He provided examples of using H-CARDD data to forecast future health care needs, to create or monitor indicators of health and health service use, and to develop new and improved ways to measure constructs.

Working with data from the identified H-CARDD cohort in these 6 projects has been highly informative but there are ongoing needs to update and expand data sources. Dr. Balogh flagged the need to continue to add to the current H-CARDD cohort, in particular to include younger individuals. Linkages to data sources from other sectors such as education, and children and youth services can help to capture a more representative cohort and to study health and health service use over the lifespan. He also spoke about the limitations of using only one type of data to answer questions, and the necessity of collecting different types of data to inform decision-making. Our program has learned about various ways to collect data, and infrastructures that can assist with ongoing monitoring and sustainability of research practice partnerships.

Changing the Trajectory

In the second part of the morning, the H-CARDD team highlighted 3 critical time points when there are opportunities to improve the health and health service trajectories for this population.

The first time point is the transition from child to adult services, a time period straddled by the health, education, children and youth, and community and social service sectors, and was presented by Dr. Jonathan Weiss. It is important to intervene at this time point because of mental and physical health problems already evident at this age, and thinking developmentally can mean making changes in sensitive periods more apt for positive outcomes. Dr. Weiss discussed individual, health systems, and cross-sector opportunities. At the individual level, he emphasized the need for access to evidence-based interventions to promote and improve mental and physical health, and to foster resilience of young

people with developmental disabilities and their families. At the health system level, he argued for an increased focus on health promotion, health monitoring, and building capacity to share health information from one provider(s) to another (e.g., from pediatricians to family physicians). He concluded with a reminder that there are a number of existing efforts to improve transitions, and it is important to build upon those efforts. Making improvements does not necessarily mean having to invent new initiatives, but working within existing processes for transition preparation and planning.

The second time point identified is the point at which aging related services are required and was presented by Dr. Ouellette-Kuntz. Persons with developmental disabilities are living longer than ever before, and experience premature aging. As they age, the supports available through the developmental sector may not be sufficient. There is concern that the aging sector may not be ready to support this unique group of individuals, and that the services offered may not always be appropriate. Dr. Ouellette-Kuntz presented two recommendations to change the trajectory at that point in time. First, providers and policymakers should make better use of existing rich clinical data to inform decision-making. Second, building capacity among providers within the health and developmental sectors should be prioritized, including their ability to work with service providers across sectors and to learn from each other. This work could be facilitated through existing partnerships, such as the Ontario Partnership on Aging and Developmental Disabilities, and the Seniors Knowledge Exchange Network.

The third time point, rather than being age or stage related, is linked to a person's service use trajectory when health needs become increasingly complex and hospital based services are required. Dr. Lunsky highlighted the importance of intervening at the individual level as soon as the person enters the hospital, particularly given the proportion of individuals with developmental disabilities who use hospitals and the likelihood of repeat visits. There are ways to improve the quality of care in a given hospital visit if the disability is recognized by health care providers and accommodations can be made. At the health system level, it is important that hospital-based health care providers have the skills and capacity to support this population. The H-CARDD primary and emergency care projects provided examples of ways to build the capacity of health care providers to support this population using 'point of care' tools and education modules. It is important that information management systems have the capacity to flag the presence of a developmental disability in a health record and that there be point people in each hospital with expertise in developmental disabilities. In addition, individuals with complex needs can benefit from coordinated care plans, such as those developed through Health Links. Other cross-sector opportunities exist; for example, creating linkages between hospitals and Developmental Services Ontario (DSO) agencies and Health Care Facilitators in the Community Networks of Specialized Care (CNSC).

Summary of Changing the Trajectory

This part of the day concluded with some lessons on implementation based on the two knowledge-to-action projects conducted by H-CARDD in primary and emergency care settings. Dr. Janet Durbin discussed the challenge of prioritizing work focused on patients with developmental disabilities when, despite high needs and significant costs, they remain a small portion of the population. Staff 'buy-in' is critical, which can be facilitated by showing the relevance of these tools to their settings, and emphasizing practice change opportunities that fit and are feasible within existing initiatives. Dr. Durbin

emphasized the importance of ‘on the ground’ and senior level champions and starting with small changes as a strategy, and the benefits of implementation teams that include internal as well as external people.

Possibilities for Action

Given our findings and lessons learned, there are many opportunities to improve the health and health service trajectories of this population in Ontario policies and practices. The final part of the provincial meeting consisted of 10 small groups that discussed the implications of H-CARDD research findings for existing frameworks and initiatives, and to inform the development of strategic actions. Following the presentations on data discoveries and changing the trajectories, mixed groups of decision-makers, planners, and service providers from different sectors took part in discussions facilitated by an H-CARDD scientist and recorded by an H-CARDD staff member.

The groups discussed immediate and longer term opportunities to make this population visible through efforts and initiatives specific to developmental disabilities (e.g., Primary Care Initiative on Developmental Disabilities, DSO, etc.) and broader strategies (e.g., Patients First: Action Plan for Health Care, Open Minds Healthy Minds Ontario’s Comprehensive Mental Health and Addictions Strategy, etc.) where people with developmental disabilities fit but are not emphasized. Through thematic analysis, a total of 6 overarching themes were identified. Topics falling under all 6 themes were discussed at each of the 10 tables and are briefly outlined here. Table 1 provides a visual representation of the 6 themes generated, which are:

1. Investing and utilizing data at the system and individual levels: Across groups, the value of data to drive future decision-making was emphasized. Indeed this was a core lesson of the H-CARDD program to date. Data is needed at the system level (e.g., to evaluate and inform policies), and the individual level (e.g., a centralized system for identifying developmental disabilities). Flagging that a person has a developmental disability is the first step toward improving their care. This information needs to be available across sectors, but is complicated by very real privacy considerations and concerns. However, identifying developmental disabilities can enhance the quality of care provided to the patient, and can also lead to changes in service use patterns across health care settings.

2. Individualizing clinical care with common tools across settings: Improved clinical care is the priority for everyone but it was thought important for health care providers to individualize their approaches in meeting the unique needs of people with developmental disabilities. This is very much in keeping with the Patients First: Action Plan for Health Care, which aims to improve access to coordinated and integrated care for all Ontarians. There was agreement that certain key processes and tools would have broad benefits and should be widely promoted, namely the ‘health check’ and communication tools/care plans to assist with communication across health service providers.

3. Improving service access, coordination and navigation: Across groups, the importance of improved access to services, and service coordination and navigation was highlighted. This need is also recognized in various policy and strategy documents, including Patients First: Action Plan for Health Care, the Ontario Special Needs Strategy, and the Aging at Home Strategy. Key existing structures that were emphasized included DSO, CNSC, and for those with more complex health needs, the Health Links. As the front door to adult developmental services, DSO agencies could share information on health care, particularly around the importance of health checks, and health communication tools. Health Care Facilitators, through the CNSCs across the province could also be available to work with the health sector and DSO to help individuals with their health care navigation. Modifying the coordinated care planning process within Health Links for this population was considered important, with lessons that could be shared by early adopters of this initiative.

4. Fostering cross-sector relationships: Across groups, cross-sector relationships and collaboration was considered a crucial aspect of moving forward. This was considered to be important both at the clinical level, in terms of allowing for cross-sector teams to engage with and follow patients across community, health and long term care settings, and at the system level (e.g., networking breakfasts of service providers in local jurisdictions). The need for seamless, cross-sector coordination is already flagged in key policy and strategy documents, but the next step is to share information about how this is being done successfully in different parts of the province.

5. Taking a lifespan approach to proactive care and health promotion: There was strong agreement that efforts to improve health care should begin early and be maintained across the lifespan, with a particular emphasis on transitions (e.g., child to adult care, adult services to aging services). Planning is crucial and begins with early identification of developmental disabilities and additional health care issues. In shifting from a crisis-driven to a preventative approach to care, many opportunities can emerge that focus on health promotion. Existing health promotion efforts for the general population need to be modified so they can effectively target and be accessed by people with developmental disabilities.

6. Promoting education of health care professionals, service users, and caregivers: Across groups, it was suggested that there are immediate opportunities to promote education and further build the capacity of health care providers, and of patients and caregivers (e.g., education tools for patients, families, and staff) to improve health and health care. Opportunities for education and specialized training for health practitioners were emphasized, including implementing this training within the medical school curriculum and having policies that ensure medical students have rotations in specific areas of vulnerability. In addition to existing educational resources developed by H-CARDD, other key educational resources that are freely available include Surrey Place's Developmental Disabilities Primary Care Initiative and McMaster University's Curriculum of Caring.

Investing and utilizing data at the system and individual levels	Individualizing clinical care with common tools across settings	Improving service access, coordination and navigation	Fostering cross-sectoral relationships	Taking a lifespan approach to proactive care and health promotion	Promoting education of health care professionals, patients, and caregivers
Data to support awareness of DD health and health care issues, informing policy and practice	Individualizing care for people with different levels of need and experiences	Service access should not have a chronological age cut-off	Broad collaborations: facilitate building relationships and communication across service providers and sectors	Early identification/recognition of DD	Education and specialized training for physicians/health practitioners
Identifying ("flagging") DD in different settings to improve patient care	Mandate for common tools/assessments/protocols for care planning	Organizational changes and opportunities for service navigation: DSO and Health Links	Clinical collaborations: building interdisciplinary teams in communities and hospitals	Shift from crisis-driven to more preventative/proactive care, e.g., 'health checks'	Education for patients and families
Stronger implementation of transition planning				Health promotion	

Table 1. Theme highlights

Conclusion

H-CARDD's provincial meeting, 'Making the Invisible Visible', led to the identification of six themes or opportunities to build on, which had strong agreement across stakeholders. Existing initiatives and efforts focused on health and service use for people with developmental disabilities should be applauded – they make great strides toward increasing the visibility of this population. Further efforts can focus on enhancing broader policies and strategies to address the needs of people with developmental disabilities and on making links between existing efforts and initiatives across sectors.

This report serves as a call for key stakeholders from across provincial sectors to focus on the six thematic areas, which offer opportunities for improving health care policy and services for individuals with developmental disabilities. As this phase of the H-CARDD program draws to a close, it is imperative that government, health care and community stakeholders, and the scientific community continue to work together to make the needs of people with developmental disabilities more visible in policy and practice. Ongoing knowledge exchange and collaboration among stakeholders and researchers can foster a better understanding of how to improve the health and health care access of Ontarians with developmental disabilities over the lifespan.



Study examines health and health service use of young adults with Autism and Developmental Disabilities

What is the research about?

The transition from child to adult health care services is difficult, particularly for young adults with developmental disabilities because of their complex health needs and because of the challenges they face in accessing services. More research is needed to understand the kinds of health issues faced by this population, how they use health care services, and where health care policy and planning can be improved.

This research sought to answer those questions for Ontario's young adults with developmental disabilities, including those with Autism Spectrum Disorder (ASD).

What did the researchers do?

The Health Care Access Research and Developmental Disabilities (H-CARDD) program studied the population of approximately 16,000 adults 18 to 24 years of age with developmental disabilities in Ontario to explore three areas, using administrative data held at the Institute for Clinical Evaluative Sciences (ICES). First, the researchers compared the demographics and health problems of young adults with developmental disabilities to young adults without such disabilities. Next, they looked back at health service use (primary care visits, psychiatrist visits, emergency department visits, and hospitalizations) of these young adults from age 14 to age 24. Finally, they compared the health problems and health service use found in young adults with ASD to those with other developmental disabilities and to young adults without developmental disabilities.

What you need to know

Young adults with developmental disabilities are more likely to have poorer overall health, have at least one psychiatric diagnosis and have higher health service use than young adults without developmental disabilities.

What did the researchers find?

The researchers found that young adults with developmental disabilities in Ontario have different rates of health problems and health care use compared to other young adults, especially for psychiatric reasons. For example, compared to young adults without developmental disabilities, those with developmental disabilities are more likely to have poorer overall health, and have at least one psychiatric diagnosis. Throughout adolescence and young adulthood, their health service use was higher than what was observed for those without developmental disabilities.

The researchers also found that while young adults with ASD have similar overall health to those with other developmental disabilities, they are more likely to receive a psychiatric diagnosis. Those with ASD are also more likely to visit a psychiatrist, but less likely to visit the emergency department compared to young adults with other developmental disabilities. Their rates of emergency department use and hospitalizations specifically for psychiatric reasons are similar to those with other developmental disabilities.

About H-CARDD

Health Care Access Research and Developmental Disabilities (H-CARDD) is a research program with the primary goal of enhancing 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, policymakers, and health care providers.

We gratefully acknowledge the Province of Ontario for their support of this project through their research grants program. The opinions, results and conclusions in this summary are those of the authors and do not reflect that of the Province or the data providers. No endorsement by the Province or the Institute for Clinical Evaluative Sciences (ICES) is intended or should be inferred. Parts of this material are based on data and information compiled and provided by the Canadian Institute for Health Information (CIHI). However, the analyses, conclusions, opinions and statements expressed herein are those of the author, and not necessarily those of CIHI.

How can you use this research?

This research supports a case for health care planning and policy development for young adults with developmental disabilities in Ontario. This is particularly true with regard to mental health care planning for those with ASD. Increased training and education of health professionals in identifying and treating mental health issues in this population can lead to prevention and early intervention. Transition plans and related supports, in particular, should be implemented to improve health outcomes for young adults with developmental disabilities.

About the researchers

Dr. Jonathan Weiss, Associate Professor from the Department of Psychology at York University and **Dr. Barry Isaacs**, Director of Research, Evaluation and Education from Surrey Place Centre, co-lead this work with the support of **Dr. Heidi Diepstra**, **Ms. Alison Chiu**, and **Mr. Drew Wilton**.

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Keywords

Developmental disabilities, transition age youth, Autism Spectrum Disorder

Do you want to know more/additional resources?

You can find more information about this research and see other Transition Age Youth information at www.hcardd.ca on the Transition Age Youth project [page](#).

Read a [summary](#) of the Transition Age Youth virtual Town Hall. View the virtual Town Hall [here](#).

View the [Transitions Toolkit](#) developed by the Developmental Disabilities Primary Care Initiative.

Read the [“Dual Diagnosis: An Information Guide”](#).

Read the [ASD Mental Health Blog](#).



Health Care Access Research
and Developmental Disabilities

www.hcardd.ca



Women with Developmental Disabilities Face Numerous Health Challenges

What is this research about?

Women with developmental disabilities have poorer medical and psychiatric outcomes than women without developmental disabilities. This research explores challenges faced by women with developmental disabilities within three main areas of women's health. First, it explores reproductive health. Historically, women with developmental disabilities had few opportunities to become pregnant and this is no longer the case. Next, researchers try to understand why many women with developmental disabilities are not getting screened for cervical and breast cancer. Finally, antipsychotic drugs are sometimes used off-label to address challenging behaviours in men and women with developmental disabilities. Research has shown that in the general population, women who use such medications are at greater risk of developing side effects than men—but what about women with developmental disabilities?

What did the researchers do?

In three projects under the umbrella of women's health, the Health Care Access Research and Developmental Disabilities (H-CARDD) program examined the following questions, using administrative data held at the Institute for Clinical Evaluative Sciences (ICES):

- What are the fertility rates, pregnancy care and outcomes of women with developmental disabilities compared to women without developmental disabilities?
- Are women with developmental disabilities who see their family physician regularly more likely to get breast and cervical cancer screening?
- Are women with developmental disabilities at a higher risk of experiencing side effects from antipsychotic medications compared to men with developmental disabilities?

What you need to know

This research highlights the importance of using a gender lens when addressing the health and health care of individuals with developmental disabilities. The voices of women with developmental disabilities need to be reflected in Ontario's women's health agenda.

What did the researchers find?

Reproductive health

Between 2002 and 2011, the researchers identified almost 4,000 deliveries for women with developmental disabilities in Ontario. Overall rates of pregnancy in women with developmental disabilities are 50% lower than the general population, but rates are similar for young women with and without developmental disabilities. Notably, women with developmental disabilities are at a higher risk for pregnancy-related medical problems and their babies are more likely to be born early and be smaller than they should be.

Breast and cervical cancer screening

The researchers found that of 5,420 eligible women with developmental disabilities, nearly half were not screened for breast cancer. Of 20,040 eligible for cervical cancer screening, two thirds were not screened. Other research has demonstrated that, in the general population, women who see their family doctor on a regular basis typically get screened for these two cancers. When it comes to women with developmental disabilities, this factor does not increase the uptake of screening.

Antipsychotic drug side effects

In the researchers' sample of men and women who were newly prescribed antipsychotic medication, women were more likely to develop blood clots, but there was no difference between women and men when it comes to developing diabetes, high blood pressure, heart attack, or stroke.

How can you use this research?

This research has implications for care providers who support women with developmental disabilities and their complex health care needs. For example, side effects need to be considered when antipsychotics are prescribed, especially if non-drug options are available. Perinatal health care needs to be better monitored, and finally, primary care providers should understand their role in improving the uptake of breast and cervical cancer screening.

About the researchers

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Keywords

Developmental disabilities, women, antipsychotic side effects, fertility, breast and cervical cancer

Do you want to know more/additional resources?

You can find more information about this research and see other women's health snapshots at www.hcardd.ca on the women's health project [page](#).

Read a [summary](#) of the women's health virtual Town Hall. View the virtual Town Hall [here](#).

Read a newsletter for caregivers entitled "[Not Skirting the Issue: Discovering Ways to End Poor Health Care for Women with Developmental Disabilities](#)"

About H-CARDD

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Adults with Developmental Disabilities and Aging

What is this research about?

Adults with developmental disabilities are living longer and are thought to age prematurely - this means that they may be accessing aging care services earlier. There is a need for a better understanding of the health and health care of those with developmental disabilities who are aging.

What did the researchers do?

Examining a sample of adults with developmental disabilities 18 to 99 years of age, the Health Care Access Research and Developmental Disabilities (H-CARDD) program projected the population's age distribution, occurrence of frailty, and use of home care and long-term care, using administrative and clinical data held at the Institute for Clinical Evaluative Sciences (ICES).

What did the researchers find?

The number of older adults with developmental disabilities in Ontario is growing. By 2021, the number of Ontarians with developmental disabilities between the ages of 45 and 84 years could be as high as 25,000.

Adults with developmental disabilities are more likely to experience frailty and to be frail at younger ages. For example, as early as 50 years of age, adults with developmental disabilities can be as frail as an 80+ year old without developmental disabilities.

What you need to know

Adults with developmental disabilities experience early onset of aging, and access home care and long term care earlier. They need timely access to appropriate aging care services.

The researchers also found that adults with developmental disabilities use aging care services more often and at much earlier ages than the general population. For example, twice as many adults with developmental disabilities than the general population were admitted to home care between 2009 and 2014.

After controlling for other factors (e.g., age, sex, mental illness and addiction, self-care skills, cognitive performance, supports received), home care users with developmental disabilities were more likely to be admitted to long-term care.

In addition, adults with developmental disabilities were admitted to long-term care 25 years earlier than the general population.

How can you use the research?

This research provides valuable evidence related to early onset of aging among adults with developmental disabilities. It should be used to advocate and plan for timely access to appropriate aging care services for this population.

About the researchers

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Keywords

Developmental disabilities, older adults, aging, home care, long-term Care

Do you want to know more/additional resources?

You can find more information about this work at www.hcardd.ca on the [aging project page](#)

View the virtual town hall [here](#)

“Using an accumulation of deficits approach to measure frailty in a population of home care users with intellectual and developmental disabilities: an analytical descriptive study” article can be found [here](#)

AHRQ report “Aging Profiles of Adults With and Without Developmental Disabilities in Ontario” can be found [here](#)

For more information on clinical resources, go to the Ontario Partnership on Aging and Developmental Disabilities (www.opadd.ca)

About H-CARDD

Health Care Access Research and Developmental Disabilities (H-CARDD) is a research program with the primary goal of enhancing 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, policymakers, and health care providers.

We gratefully acknowledge the Province of Ontario for their support of this project through their research grants program. The opinions, results and conclusions in this summary are those of the authors and do not reflect that of the Province or the data providers. No endorsement by the Province or the Institute for Clinical Evaluative Sciences (ICES) is intended or should be inferred. Parts of this material are based on data and information compiled and provided by the Canadian Institute for Health Information (CIHI). However, the analyses, conclusions, opinions and statements expressed herein are those of the author, and not necessarily those of CIHI.



Health Care Access Research
and Developmental Disabilities

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A Closer Look at Mental Illness and Addictions in People with Developmental Disabilities

What is this research about?

Although mental illnesses and addictions are common among people with developmental disabilities, little is known about people who have this combination of conditions. Health care providers may feel ill-equipped to meet the mental health needs of those with developmental disabilities because of the complex interplay of their disability with their psychiatric presentation. The limited research has focused strictly on mental illness, ignoring addictions because of the misconception that those with developmental disabilities do not access drugs or alcohol.

What did the researchers do?

The Health Care Access Research and Developmental Disabilities (H-CARDD) program examined how many of over 66,000 Ontario adults with developmental disabilities received a mental illness and/or addictions diagnosis in a two-year period using administrative data held at the Institute for Clinical Evaluative Sciences (ICES). They compared the health profiles and health care use of these individuals to other adults with developmental disabilities, and to adults without developmental disabilities. For the group with developmental disabilities and mental illnesses and/or addictions, the researchers looked more closely at those with only mental illness, those with only addictions, and those with both, and compared these three groups across a range of health areas. Health service indicators of interest included the likelihood of using physician, hospital or emergency department services; admission rates and return visits to the hospital within 30 days; and staying in hospital longer than deemed appropriate or than necessary.

What you need to know

Individuals with developmental disabilities who also have a mental illness or addiction are a sizeable and highly vulnerable group. Intensive outpatient supports and better care coordination are needed for this population.

What did the researchers find?

The researchers found that nearly 1 in 2 adults with developmental disabilities have a mental illness or addiction. Among these adults, the prevalence of addiction is twelve percent, which is higher than previously thought. Compared to other adults with developmental disabilities and to adults without developmental disabilities, adults with a mental illness or addiction are more likely to live in poorer neighbourhoods, and have a higher prevalence of serious health issues like diabetes, hypertension and asthma.

Not surprisingly, adults with mental illness or addictions on top of their developmental disabilities are more likely to have contact with physicians in the community and in hospital settings. They are also more likely to have repeat visits to hospital and emergency departments and stay in hospital longer than necessary. The researchers found that the subgroup with both mental illness and addictions are the most vulnerable. They are the most likely to live in poor neighbourhoods and have poor overall health.

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They have the highest rates of physician visits, but do not see the same primary care provider in a consistent way, and they have the highest use and repeat use of hospital and ED services.

How can you use this research?

We know that adults with developmental disabilities have serious health concerns and complex needs. However, the higher than previously reported addictions rates, poor overall physical and mental health, and patterns in service use suggest that there is a need for more intensive outpatient supports and better care coordination, especially for those who experience both mental illness and addictions. The current study helps inform the need for a major research focus on this vulnerable subgroup to better serve their needs.

About the research team

Dr. Elizabeth Lin, from the Provincial System Support Program at CAMH and **Dr. Robert Balogh**, from the Faculty of Health Sciences at UOIT, both adjunct scientists at ICES, co-lead this work with the support of **Avra Selick**, **Kristin Dobranowski**, and **Drew Wilton**.

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Keywords

Developmental disabilities, mental illness and addictions

Do you want to know more/additional resources?

You can find more information about this work at www.hcardd.ca on the mental illness and addictions project [page](#).

View a webinar on addictions [here](#).

Read a [summary](#) of the mental illness and addictions virtual Town Hall

Read a newsletter for caregivers entitled "[Let's Talk about Mental Health](#)" or the "[Dual Diagnosis: An Information Guide](#)"

Access other relevant clinical resources via the Portico website on [Dual Diagnosis](#)



Health Care Access Research
and Developmental Disabilities

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Annual Health Checks can Improve Health Care for Adults with Developmental Disabilities

What is the research about?

Adults with developmental disabilities have more health problems than other adults and more difficulties accessing health care. The 2011 Canadian Consensus Guidelines for the Primary Care of Adults with Developmental Disabilities, supported by international research, recommend that adults with developmental disabilities have annual comprehensive preventive health reviews to identify and manage health concerns. The “Health Check” has been described as the most important investment in the primary health care of people with developmental disabilities in the 21st century. Yet, in Ontario, only one in five adults with developmental disabilities receives a “Health Check.”

What did the researchers do?

The Health Care Access Research and Developmental Disabilities (H-CARDD) program offered support to three Family Health Teams in different regions of Ontario to implement “Health Checks”, and evaluated factors needed for successful implementation. The intervention includes: 1) identifying patients with developmental disabilities in the practice; 2) inviting them in for a Health Check, and; 3) enabling the health review to be more consistent with guidelines.

What did the researchers find?

Two of the three practice sites successfully implemented the intervention. Key factors in obtaining buy-in were a pre-existing interest in the care of patients with developmental disabilities or vulnerable populations combined with the work of on-site champions.

What you need to know

“Health Checks” in primary care can have significant positive impacts for individuals with developmental disabilities. With planning and support, primary care practices can implement changes so that patients with developmental disabilities are more likely to receive a Health Check.

Also important were designing an implementation strategy that fit with current work processes and providing accessible supports for staff to do the work, including an onsite implementation facilitator with protected time.

Each team developed a process for identifying patients to invite to the Health Check and dedicated some clerical time to making the invitation phone calls. To help modify their standard approach to care, staff were provided with education about developmental disabilities along with clinical support tools, such as local resource lists and reminders about common medical issues. When possible, these tools were embedded in the electronic medical record system.

Patients who received an invitation were more likely to come in for a Health Check and patients who came in for the Health Check received more preventive tests than those who did not. Most of the staff who performed the Health Check felt that it benefited the patients and fit in their setting. However, staff comfort in caring for patients with developmental disabilities still varied and many staff indicated a need for more preparation.

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Keywords

Implementation, developmental disabilities, primary care, health check

Sustaining a Health Check program can be promoted by:

- A routine process for identifying patients with DD
- Documentation of DD in the patient's electronic medical record
- A process for patients to receive invitation phone calls
- Tools and resources to make care more efficient and effective
- Including Health Checks in ongoing Quality Improvement programs

How can you use this research?

Provincial bodies can play a leadership role in supporting Health Check implementation. Family Health Teams and other primary care providers interested in improving their practices with patients with developmental disabilities can access clinical resources and read about implementation strategies in the Developmental Disabilities Primary Care toolkit . Teaching videos and presentations are available in the toolkit, along with several clinical tools and implementation guides. It is important that local communities work together with provincial bodies to encourage regular Health Checks. Individuals with developmental disabilities and their caregivers can prepare for Health Checks and take an active role in promoting their health and using resources developed for them.

About the researchers

Ian Casson, from the Department of Family Medicine at Queen's University worked together with **Laurie Green** and **Andrea Perry** from St Michael's Hospital and **Yona Lunsky**, from CAMH to develop this intervention. **Janet Durbin**, from CAMH led the evaluation of this project with the support of **Avra Selick**, **Natasha Spassiani** and **Megan Abou Chacra**.

Do you want to know more/additional resources?

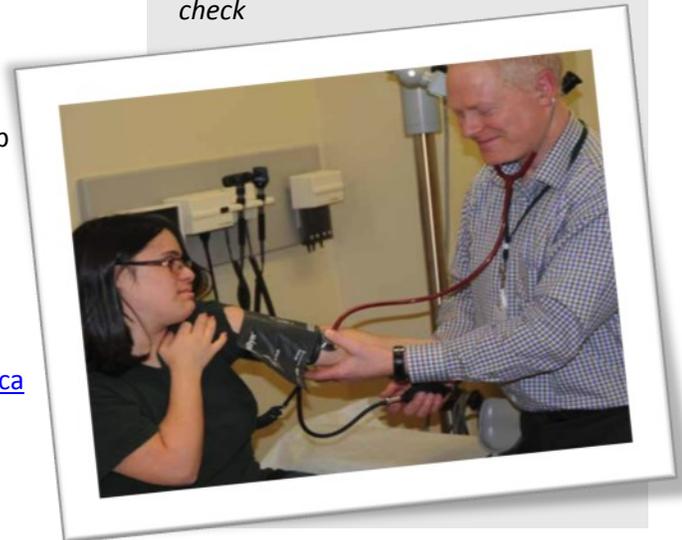
You can find more information about this research at www.hcardd.ca or on the Family Health Team project [page](#)

Watch a [video](#) for patients and caregivers on health of people with developmental disabilities

Watch a [video](#) for clinicians on improving primary care for patients with developmental disabilities

Our website also has [patient](#) and [caregiver](#) tools to help prepare for a primary care visit

View the [Primary Care Guidelines](#) on the Surrey Place [website](#).



Health Care Access Research
and Developmental Disabilities

www.hcardd.ca



Improving emergency care for people with developmental disabilities

What is the research about?

One in two adults with developmental disabilities in Ontario will visit their emergency department (ED) at least once in two years. They are more likely than other adults to visit the ED, and they are more likely to have repeat visits. ED visits are stressful for those with developmental disabilities, their caregivers, and ED staff. The quality of visits could be improved with better recognition, communication, planning and linkages between hospital and community resources.

What did the researchers do?

The Health Care Access Research and Developmental Disabilities (H-CARDD) program worked with three emergency departments in Ontario to improve the quality of the visit for patients with developmental disabilities. The researchers worked with a team at each ED to identify and implement relevant practice changes. The researchers assessed barriers and facilitators to implementation, and evaluated the extent to which the planned changes were implemented.

What did the researchers find?

Each site implemented the intervention slightly differently to fit with their unique context. Implementing change in EDs is difficult and the three sites achieved varied levels of success in their change efforts. Obtaining senior leadership support was key to creating interest and momentum for change, and implementation was helped by having committed onsite clinical leads who protected some staff time to implement the changes. It was also important to align the changes with existing hospital initiatives and priorities.

What you need to know

Recognizing and communicating information about developmental disabilities in the emergency department is the first step to improving care practices. Hospital staff can improve their approach through education and the use of clinical tools.

The practice changes focused on three core components: (1) Develop a process for identifying patients with developmental disabilities. Some staff were concerned about making the right diagnosis and using the right language but flagging potential disability issues is key so that the clinical team is alerted to remember to adapt their care; (2) Provide staff with education about developmental disabilities and with ready access to resources such as local area resource lists, communication tip sheets, discharge forms; (3) Improve communication between the ED and the community. This includes health care passports that provide staff with important information about the patient, and tailored discharge forms that can provide important follow-up information for the patients and their families, and also for community providers they see after they leave the ED.

At the end of the study, two thirds of staff reported being aware of strategies to identify developmental disabilities, most communicated whether a patient had a developmental disability to colleagues and almost all reported adapting their approach at least sometimes. However, results indicated that staff need further education and training, with awareness of community resources still low.

Many staff recognized the need to improve care, but some were worried about having enough time to do so.

Continuing this improvement work will require embedding practice changes into normal ED work flows. One site is creating systematic processes to help staff identify patients with developmental disabilities at triage, documenting the disability in the patient's chart, informing medical staff when they arrive in the ED, and alerting ED social workers to assist with discharge planning. Ongoing evaluation is important.

How can you use this research?

Emergency departments interested in improving their practices for patients with developmental disabilities can access clinical resources and read about implementation strategies in the Developmental Disabilities Emergency Care toolkit, through H-CARDD.

Community agencies and community-based health care providers can work together with hospitals to develop patient care plans, and encourage the use of communication tools such as the 'About Me' passport. It is important that local communities collaborate to encourage consistent use of tools and communication mechanisms. Individuals with developmental disabilities and their caregivers can prepare for emergencies and use resources developed for them.

About the researchers

Jacques Lee, Research Director in Emergency Medicine at Sunnybrook Health Sciences Centre worked together with **Yona Lunsky**, Director of H-CARDD and Clinician Scientist at the Centre for Addiction and Mental Health and **Andrea Perry**, implementation facilitator, to develop this intervention. **Janet Durbin**, an Independent Scientist in the Provincial Support Services Program at the Centre for Addiction and Mental Health led the evaluation of this project with the support of **Avra Selick**, **Natasha Spassiani**, and **Megan Abou Chacra**.

Do you want to know more/additional resources?

You can find more information about this research and access the ED toolkit on the Emergency Care project [page](#).

Watch a [Video](#) for patients and caregivers on what to expect when you visit the emergency department

Our website also has [patient](#) and [caregiver](#) tools to help prepare for an emergency department visit

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Keywords

Developmental disabilities, emergency departments, quality improvement



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