



Health Care Access Research
and Developmental Disabilities

HEALTHCARE ACCESS RESEARCH AND DEVELOPMENTAL DISABILITIES (H-CARDD)

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Women and Mothers with Developmental Disabilities: Priorities for Action

Summary of Town Hall Proceedings

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About H-CARDD

Health Care Access Research and Developmental Disabilities (H-CARDD) is a research program that aims to enhance the overall health and wellbeing of individuals with developmental disabilities through improved healthcare policy and improved services. H-CARDD research is conducted by dedicated teams of scientists, policymakers, and health care providers, working collaboratively.

H-CARDD's partners include the Ontario Ministry of Community and Social Services, the Ontario Ministry of Health and Long-Term Care, the Centre for Addiction and Mental Health, the Institute for Clinical Evaluative Sciences, Surrey Place Centre, the University of Toronto, the University of Ottawa, Queen's University, York University, Lakehead University, Sunnybrook Hospital, the University of Ontario Institute of Technology, and Women's College Hospital.

H-CARDD is currently funded by the Canadian Institutes of Health Research Partnerships for Health System Improvement program and the Ontario Ministry of Health and Long-Term Care Health Systems Research Fund.

For more information about H-CARDD, please visit www.hcardd.ca.

Disclaimer:

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Executive Summary

Research has shown that women with developmental disabilities have poorer medical and psychiatric outcomes than women without developmental disabilities, particularly with regards to reproductive cancer screening and perinatal health. These women also experience economic and social discrimination based on both their gender and developmental disability status, which makes them especially vulnerable to inequities.

In January 2015, researchers studying the health and health care of women and mothers with developmental disabilities in Ontario hosted an interactive Town Hall to discuss findings related to the following questions:

- 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 at higher risk of antipsychotic medications side effects (e.g., diabetes, high blood pressure and blood clots), compared to men with developmental disabilities?
- What factors could explain inequities in uptake of breast and cervical cancer screening in women with developmental disabilities, compared to women without developmental disabilities?

This free and interactive Town Hall was broadcast to 27 Ontario Telemedicine Network (OTN) sites across Ontario and to 49 live webcast connections (OTN and Adobe Connect). The overall goal was to engage in a discussion with H-CARDD's key knowledge users about these findings and about priorities for action in order to improve the health and health care of women and mothers with developmental disabilities. This report provides a summary of the Town Hall proceedings, with a particular focus on the discussion of findings in relation to these three topic areas and the priorities for action identified by Town Hall participants.

A key theme coming out of this Town Hall was the importance of using a gender lens when addressing the health and health care of individuals with developmental disabilities. Women with developmental disabilities are less likely to receive breast and cervical cancer screening and are more likely to have poorer health in key areas and to experience negative health outcomes, particularly for psychiatric and perinatal health

care. Participants in the Town Hall also helped articulate a call to action to develop a health agenda specifically for women with developmental disabilities with a particular focus on the need for:

- Identifying strategies that will inform the application of a gender lens for the health and health care of women with developmental disabilities.
 - Training and resources for health care providers to improve their capacity to support women with developmental disabilities.
 - Resources for women with developmental disabilities to help them better manage their health care.
- Ensuring that the voices of women with developmental disabilities are reflected in Ontario's women's health agenda.
- Further research regarding the unique health care needs of women and mothers with developmental disabilities

Introduction

Persons with developmental disabilities, such as Autism or Down syndrome, are one of the most vulnerable populations because of their complex health needs and because of the challenges they face in accessing health care services. In response to this issue, an interdisciplinary program, Health Care Access Research and Development Disabilities (H-CARDD) was established in 2010. Through H-CARDD, researchers work with Ontario policy makers and service providers to: 1) monitor the health of persons with developmental disabilities through new research and 2) to improve practice in primary and emergency care through the implementation of evidence-based practices.

Early H-CARDD work resulted in the creation of a cohort of over 66,000 adults in Ontario with developmental disabilities. This cohort, the largest of its kind, provided an opportunity to study health care and outcome use, beginning first with the quality of primary care for individuals with developmental disabilities in Ontario.¹ Since 2013, H-CARDD has been using this cohort to gain a better understanding of issues related to specific subgroups of individuals with developmental disabilities who are particularly vulnerable. One such group, women with developmental disabilities, are known to have poorer medical and psychiatric outcomes than women without developmental disabilities, particularly with regards to reproductive cancer screening and perinatal health. These women can also experience economic and social discrimination based on both their gender and developmental disability status, which makes them especially vulnerable to inequities.²

In January 2015, researchers leading a study on the health of women and mothers with developmental disabilities hosted an interactive Town Hall to present preliminary findings related to the following questions:

- What are the fertility rates, pregnancy care and outcomes of women with developmental disabilities compared to women without developmental disabilities?

¹ See Lunsky Y, Klein-Geltink JE, Yates EA, eds. Atlas on the Primary Care of Adults with Developmental Disabilities in Ontario. Toronto, ON: Institute for Clinical Evaluative Sciences and Centre for Addiction and Mental Health; 2013. Available online at <https://www.porticonetwork.ca/documents/38160/99698/Atlas+revised+2014/c2d68a41-ed3d-44dc-8a14-7f30e044c17e>.

² Refer to second chapter in Lunsky et al., (2013) for details.

- Are women with developmental disabilities at higher risk of antipsychotic medications side effects (e.g., diabetes, high blood pressure and blood clots), compared to men with developmental disabilities?
- What factors could explain inequities in uptake of breast and cervical cancer screening in women with developmental disabilities, compared to women without developmental disabilities?

The overall goal of this Town Hall was to engage in a discussion with H-CARDD's key knowledge users about these findings and about priorities for action in order to improve the health and health care of women and mothers with developmental disabilities. This report provides a summary of the Town Hall proceedings, with a particular focus on the priorities for action identified by Town Hall participants.³

³ For more context related to the findings presented in this summary, please view the complete video of the Town Hall, accessible on: <https://www.porticonetwork.ca/web/hcardd/women/town-hall-women>

Town Hall Process

Participation in the Town Hall was free and open to anybody but was specifically targeted to policy/decision makers, service providers, caregivers/families and advocates who have a particular interest in developmental disabilities. The event was advertised with a flyer distributed through relevant stakeholder networks and through postings on the H-CARDD website, Ontario's Evidence Exchange Network (EENet), and the Ministry of Community and Social Services' (MCSS) *Spotlight on Transformation* newsletter.

In order to reach as many participants as possible, the presenters hosted the Town Hall from the Surrey Place Centre and the event was broadcast through the Ontario Telemedicine Network (OTN) and Adobe Connect. Participants were encouraged to attend in person at any OTN site across Ontario (including at the Surrey Place Centre) in order to better engage with peers, colleagues and new acquaintances who share the common goal of supporting the health and health care of individuals with developmental disabilities. Those who were not able to access an OTN site were able to participate by live Webcast through the OTN or through Adobe Connect. A total of 27 OTN sites across Ontario were connected to the Town Hall in addition to 49 live webcast connections (OTN and Adobe Connect).

The Town Hall was a combination of presentations on the research findings and a discussion. Questions and comments provided by participants, either directly to the presenters through OTN, through email, or through the webcast platforms, were responded to during the session.

ABOUT THE PRESENTERS

Virginie Cobigo (PhD, C. Psych) is an assistant professor at the School of Psychology at the University of Ottawa, and a clinical psychologist. She has experience in working with persons with developmental disabilities in Canada, France, and England. Her research aims to build evidence to support improvements in services for adults with developmental disabilities.

Simone Vigod (MD, MSc, FRPC) is a psychiatrist and a scientist at Women's College Hospital, Toronto. She is an assistant professor in the department of Psychiatry at the University of Toronto. Her research is focused on optimizing outcomes for women with mental illness during pregnancy and the post-partum period.

Hilary Brown (PhD, MSc) is a postdoctoral fellow at Women's College Hospital and is funded by the Canadian Institutes of Health Research to study the health of mothers with developmental disabilities and their infants.

Natasha Plourde (BSc) is a doctoral candidate at the University of Ottawa, studying sexual education programs for persons with developmental disabilities and the uptake of cancer screening in women with developmental disabilities.

Summary of Proceedings

MOTHERS WITH DEVELOPMENTAL DISABILITIES

The population studied

There were 21,181 women with developmental disabilities who were between 18 and 49 years old in Ontario in 2009. Between 2002 and 2011, there were 3,932 obstetrical deliveries among these women.

Key findings

- Women with developmental disabilities have lower fertility rates overall, but young women with developmental disabilities have similar fertility rates to young women without.
- Pregnant women with developmental disabilities have pre-existing social and health risks, including mental health issues, that may affect pregnancy outcomes.
- Women with developmental disabilities have increased risk for several serious pregnancy complications, such as pre-eclampsia or eclampsia and blood clots.

Priorities for action

Through practice:

- Develop appropriate screening tools and training for service providers to ensure that co-occurring mental health issues among pregnant women with developmental disabilities are not missed or assumed to be a symptom of their developmental disability
- Ensure that appropriate care pathways are in place for pregnant women with developmental disabilities who have mental health issues.

Through research, investigate:

- whether existence of pre-existing mental health issues among women with developmental disabilities increases their risks for complications during pregnancy and/or mental health issues following pregnancy (e.g., post-partum depression)
- whether level of mobility is associated with complications during pregnancy for women with developmental disabilities - for example, higher risk of blood clots
- whether women with developmental disabilities find out about their pregnancies later than women with developmental disabilities and whether this late knowledge increases their risk for complications during pregnancy
- whether risks for complications during pregnancy differ for women with developmental disabilities who had one obstetric delivery as compared to those who had two or more obstetric deliveries.
- what the reasons are for the increased prevalence of pregnancy in younger age groups among women with developmental disabilities
- rates of prescription of birth control pills and abortions among women with developmental disabilities as compared to women without developmental disabilities

“To me, the thing that was jarring was the rate of pre-existing mental health issues among pregnant women with developmental disabilities. It just seems like that’s the elephant in the room. They need mental health supports and screenings. It has such a huge impact on children so it’s particularly important for mothers.”

WOMEN WITH DEVELOPMENTAL DISABILITIES AND ANTIPSYCHOTIC SIDE EFFECTS

The population studied

Women (N=1,457) and men (N=1951) with developmental disabilities in Ontario who were prescribed an antipsychotic medication for the first time between 2009 and 2010 were followed for up to three years to compare differences in rates of newly developed diabetes.

Key findings

Women and men have similar risk for diabetes after starting antipsychotic medication, but women may die sooner than men after starting a new antipsychotic medication.

Priorities for action

Through practice:

- Provide specialized training, resources and supports to ensure a multi-disciplinary approach to appropriate screening, assessment, diagnosis and treatment of psychosis, and to ensure that medications are not being used inappropriately to manage behavioural issues or to address behaviours resulting from comorbid medical issues.
- Ensure that women with developmental disabilities have appropriate supports in place (e.g., medical, social) as they transition off of antipsychotic medications.
- Implement a process to study the reasons for death in this population and whether mortality is related to gender.

“In cases of suspected schizophrenia in women with developmental disabilities, there needs to be a historical workup to look at the presence of autism that would better explain the symptomology because the profiles can look similar. Unfortunately, a lot of times the history has been lost with these women, so it's tricky. But it's something, particularly in relation to the education piece, that we have to be mindful of and spread the mindfulness around: when you have a woman with a developmental disability and you are thinking of prescribing an antipsychotic medication, it is important to think of what else might be going on.”

Through research, investigate:

- the clinical reasons for prescribing antipsychotic medications to women with developmental disabilities and whether medication is sometimes used inappropriately to manage difficult behaviours or to address symptoms of underlying medical conditions.
- the causes of death for women with developmental disabilities who were prescribed antipsychotic medication - for example to determine whether the increased risk for negative outcomes are directly associated with antipsychotic use (e.g., medications cause arrhythmias) and/or an interaction between medications and pre-existing health conditions.

WOMEN WITH DEVELOPMENTAL DISABILITIES AND BREAST AND CERVICAL CANCER SCREENING

The populations studied

- Rates of breast cancer screening in Ontario were compared for 50-64 year old women with developmental disabilities (N=7022) and without developmental disabilities (N=402,589).
- Rates of cervical cancer screening in Ontario were compared for 18-64 year old women with developmental disabilities (N=26,301) and without developmental disabilities (N=1,304,279).

Key findings

- Women with developmental disabilities are at risk for under-screening for breast and cervical cancers.
- Women who have a doctor that they see regularly (high continuity of care) are not more likely to receive these kinds of screening.

Priorities for action

Through practice:

- Develop and disseminate resources to service providers and women with developmental disabilities:
 - For service providers, resources could focus on the importance of conducting breast and cervical cancer screening and on strategies to encourage and support women during the screening process
 - For women with developmental disabilities, resources should focus on describing the process to enhance their readiness and comfort with breast and cervical cancer screening processes; if readiness is found to differ, for example, among women with developmental disabilities who have different living arrangements or levels of functioning, resources should be tailored and targeted accordingly

“We need to provide training and extra resources to primary care physicians and even resources for women with developmental disabilities themselves about the cancer screening process and procedure and how to ready themselves.”

Through research, investigate:

- Why women with developmental disabilities are not receiving guideline recommended screening for breast and cervical cancer, particularly in the context of the finding that women with developmental disabilities who have high continuity of care are no more likely to receive these types of cancer screening. Potential reasons may include:
 - Physicians lack the necessary training, communication skills and comfort to conduct breast and cervical cancer screening for women with developmental disabilities

- Beliefs among health care providers that women with developmental disabilities are not sexually active and therefore do not require cervical cancer screening
- If the level of functioning of women with developmental disabilities impacts their rates of breast and cervical cancer screening
- If there are differences in the rates of cervical cancer among women with and without developmental disabilities
- Whether rates of breast and cervical cancer screening for women with developmental disabilities differs for different categories of living arrangements

Call to Action

The research and stakeholder perspectives reflected in this Town Hall reinforce how gender matters for the health and health care of individuals with developmental disabilities. We now know that women with developmental disabilities in Ontario are less likely to receive breast and cervical cancer screening. They are also more likely to have poorer health in key areas and to experience negative health outcomes following psychiatric and perinatal health care. This section presents a call to action to develop a health agenda specifically for women with developmental disabilities with a particular focus on the need for:

- Identifying strategies that will inform the application of a gender lens for the health and health care of women with developmental disabilities:
 - **Training and resources for health care providers** to improve their capacity to support and engage women with developmental disabilities.
 - **Resources for women with developmental disabilities** to help them better manage their health care. These resources should reinforce the important role women play in their own health care, the importance of breast and cervical screening and preventative care and what women with developmental disabilities and their families can do to advocate for and support their health. Where applicable, existing health resources for women should be reviewed for their accessibility to women with developmental disabilities.
- **Ensuring that the voices of women with developmental disabilities are reflected in Ontario's women's health agenda.**
- **Further research regarding the unique health care needs of women and mothers with developmental disabilities**

H-CARDD Town Hall Series

Health Status and Service Use in Transition Age Youth with Developmental Disabilities

Drs. Barry Isaacs and Jonathan Weiss

December 11, 2014 – 1:00 to 3:00 pm

To access the video of the Town Hall, please visit:

<https://www.porticonetwork.ca/web/hcardd/youth/town-hall-tay>

Women and Mothers with Developmental Disabilities: Priorities for Action

Dr. Virginie Cobigo, Dr. Simone Vigod, Dr. Hilary Brown, and Ms. Natasha

Plourde

January 19, 2015 – 12:00 to 2:00 pm

To access the video of the Town Hall, please visit:

<https://www.porticonetwork.ca/web/hcardd/women/town-hall-women>

Gaps in health care for individuals with DD-plus (developmental disability plus either mental health or addictions issues)

Drs. Elizabeth Lin and Rob Balogh

February 12, 2015 – 10:00 am to 12:00 pm

To access the video of this Town Hall, please visit:

<https://www.porticonetwork.ca/web/hcardd/dual-diagnosis/town-hall-dd-and-addiction>

Aging and Developmental Disabilities: Frailty, Home Care and Long-term Care

Dr. Lynn Martin, Dr. H el ene Ouellette-Kuntz, and Ms. Katherine McKenzie

February 19, 2015 - 1:00 – 3:00 pm

To access the video of this Town Hall, please visit:

<https://www.porticonetwork.ca/web/hcardd/aging/town-hall-aging>

If you would like to receive updates about these or upcoming H-CARDD events and resources, please send an email to hcardd@camh.ca to be added to the H-CARDD distribution list.



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