HCARDD

Health Care Access Research and Developmental Disabilities

HEALTHCARE ACCESS RESEARCH AND DEVELOPMENTAL DISABILITIES (H-CARDD)

February 2015

Gaps in Health Care for Individuals with Developmental Disabilities and Mental Illness or Addiction Disorders

Summary of Town Hall Proceedings

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CONTENTS

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

Persons with developmental disabilities (DD) 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. We know that almost half of adults with DD also have a co-occurring mental illness or addiction disorder, a reality that makes their health and health care situations even more challenging. A better understanding of this population and their service use patterns is important to ensure that they receive high quality care.

In February 2015, researchers leading the study of adults with DD and mental illness and addiction disorders hosted an interactive Town Hall to describe and compare the following groups in terms of who they are, what kinds of health problems they have, and how they use health care:

- Individuals with DD plus a mental illness and/or addiction
- Individuals with DD but no mental illness or addiction
- Individuals without DD

This free and interactive Town Hall was broadcast live from the Surrey Place Centre in Toronto to 40 Ontario Telemedicine Network (OTN) sites across Ontario and to 93 live webcast connections (OTN and Adobe Connect).

PROFILE OF ADULTS WITH DEVELOPMENTAL DISABILITIES WHO HAVE A MENTAL ILLNESS OR ADDICTION DISORDER

Findings: Nearly half of adults with DD also have a mental illness or addiction disorder. These adults were also found to have a higher prevalence of all chronic diseases studied (asthma, hypertension, chronic obstructive pulmonary disorder (COPD), asthma and congestive heart failure), compared to adults with DD only and adults without DD.

Compared to both adults with DD only and adults without DD, adults with mental illness or addiction disorders were found to have higher use of services (i.e., use of any physician services, emergency department (ED) visits, hospitalizations). They were also more likely to have repeat hospitalizations and visits to the ED within 30 days of leaving hospital or ED.

Discussion: Participants in the Town Hall were asked to discuss specifically what has worked well to prevent repeat ED visits or repeat hospitalizations. Responses tended to focus on what was needed in the system. Their suggestions included:

- The need for improved **access to appropriate service, supports and staffing in the community** – ideally available locally, with accessible hours of operation and with supports to families and for navigation within and across services.
- The important role that **primary health care should play in managing and coordinating the health care of individuals with DD**, including the early detection of DD itself, mental health and addiction issues and physical health problems.
- The need for **training for a range of health and social service providers**, including hospital, ED and primary health care staff.
- The **use of support/care plans** to ensure that care planning is proactive, includes protocols to manage crises and is broadly shared with the individual's **circle of care.**

A CLOSER LOOK AT ADULTS WITH DEVELOPMENTAL DISABILITIES AND DISORDER

Findings: Among adults in who have a mental illness or addiction disorder, most (~87%) had a mental illness. Those with an addiction, while they were small in number (~13%), showed clear evidence of disproportionately higher need. They were more likely to be male and live in the poorest neighbourhoods. They were also more likely to have chronic obstructive pulmonary disease (COPD) and asthma, compared to adults with DD who had only a mental illness. In terms of service use, adults with DD who had both a mental illness and addiction disorder had higher rates of both visits and repeat visits to the EDs and hospitals, as compared to adults with DD who had only a mental illness or only an addiction disorder.

Discussion: Town Hall participants discussed the potential reasons for addiction among adults with DD, including their marginalization in society (e.g., poorer living conditions increasing exposure to substances), the relief from suffering that substances offer in the absence of more appropriate services and supports (i.e., self-medication), and little to no access to addiction services and supports. Participants highlighted that individuals

with mild DD may be particularly vulnerable to addiction because their disabilities are either not recognized or are not severe enough to qualify for already scarce services and supports.

Participants were asked to specifically discuss what is needed to address the needs of individuals with addictions or the combination of mental illness and addiction disorder. Participants emphasized the need for increased access to integrated, appropriate and affordable addictions and mental health programming. Strategies to achieve this included:

- Increasing the capacity of psychiatric and other specialized services to address issues of addiction
- Developing mechanisms for collaboration and cross-training to build capacity in community services to address mental illness and addiction
- Providing a single point of access
- Ensuring adequate transition supports for individuals involved in the justice system
- Ensuring that a multi-disciplinary team is planning and coordinating care
- Increasing the awareness of service providers, individuals with DD and their families about existing community resources
- Addressing the link between low socio-economic status and addiction and mental illness by increasing access to high quality, supportive housing and healthy recreational and social opportunities
- Expanding efforts for cross-ministerial collaboration to better share data/resources and to enhance communities' response to the needs of individuals with DD

SUGGESTIONS FOR FUTURE RESEARCH

Participants provided the following suggestions for future research that were felt to be relevant to understanding the health and health service use of adults with DD who have mental illness and/or addiction disorders:

- Perceptions of care of individuals with mental illness and/or addiction disorders, including what worked, what didn't, and what was missing
- Rates of follow-up for chronic conditions
- How the health and health care of individuals varies by:
    - Gender
    - Level of disability
    - Type of diagnosis
- The extent to which issues impacting mental illness and addiction, including access to appropriate services, are a function of DD or are more broadly applicable to the general population
- Health and health care access for individuals with DD involved in the justice system
- Evaluation of the impact of initiatives designed to better address the needs of individuals with DD, including those with mental illness and/or addiction disorders
- Trends over time in the detection of DD, mental illness and addiction disorders, and access to health care

Introduction

Persons with developmental disabilities (DD), 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 in 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 DD 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 DD. This cohort, the largest of its kind, provided an opportunity to learn more about health care use and outcomes, beginning first with the quality of primary care for individuals with DD in Ontario.[1] Since 2013, H-CARDD has been studying this cohort to gain a better understanding of issues related to specific subgroups of individuals with DD known to be particularly vulnerable. One such group is adults with DD who also have a mental illness or addiction disorder. We know that almost half of adults with DD also have a co-occurring mental illness and/or addiction disorder[2], a reality that makes their health and health care situations even more challenging. A better understanding of this population and their service use patterns is important to ensure that they receive high quality care.

In February 2015, researchers leading the study of adults with a DD and a mental illness or addiction disorder hosted a Town Hall to describe and compare the following groups in terms of who they are, what kinds of health problems they have, and how they use health care:

- Individuals with DD plus a mental illness and/or addiction
- Individuals with DD but no mental illness or addiction
- Individuals without DD

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[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 Lunsky et al. (2013) as above.

The overall goal of this Town Hall was to engage in a discussion with H-CARDD's key knowledge users about how the findings fit with their experiences across Ontario and about what recommendations should flow from this research in order to improve the health and health care access of adults with DD who also have a mental illness and/or addiction disorder. This report provides a summary of the Town Hall proceedings, with a particular focus on the feedback and discussion shared by Town Hall participants.

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 DD. The event was advertised through a flyer distributed by 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). 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 DD. Those who were not able to access an OTN site were able to participate by live Webcast through the OTN or through Adobe Connect.

The Town Hall was a combination of presentations on the research findings and "break out" sessions focused on specific discussion questions. Participants were asked to provide a summary of their discussions through email. Questions were also posed directly to the presenters through OTN, through email, or through the webcast platform and were responded to live during the session. Those participating by Adobe Connect could "chat" online with other participants during the breakout session. A total of 40 OTN sites across Ontario were connected to the Town Hall, in addition to 93 live webcast connections (OTN and Adobe Connect).

ABOUT THE PRESENTERS

Elizabeth Lin, PhD is an Independent Scientist in the Provincial System Support Program at the Centre for Addiction and Mental Health, an Associate Professor with the Department of Psychiatry at the University of Toronto, and adjunct faculty at the Institute of Clinical Evaluative Sciences. She is fairly new to the field of developmental disabilities but has been active for nearly 25 years in using large Ontario datasets to describe how people use mental health and addictions care and to highlight areas where service delivery might be improved.

Robert Balogh, PhD, BHSc (PT) is an Assistant Professor at the University of Ontario Institute of Technology, an adjunct scientist at the Institute for Clinical Evaluative Sciences, and a physiotherapist. His recent research looks at chronic diseases in people with developmental disabilities and how often they get hospitalized. Over the years, he has helped to support people with developmental disabilities in different settings.

Summary of Proceedings

PROFILE OF ADULTS WITH DEVELOPMENTAL DISABILITIES WHO HAVE A MENTAL ILLNESS OR ADDICTION DISORDER

Key research findings

The health status and health care service use of the following three groups were compared:

- Approximately 30,000 adults with DD in Ontario who have a mental illness and/or an addiction disorder[3]
- Approximately 35,000 adults in Ontario who have only a DD
- Approximately 2.8 million adults in Ontario without a DD

Health status: Nearly half of adults with DD also have a mental illness or addiction disorder. These adults were also found to have a higher prevalence of all chronic diseases studied (asthma, hypertension, chronic obstructive pulmonary disorder (COPD), asthma and congestive heart failure), compared to adults with DD only and adults without DD.

Health service use: Compared to both adults with DD only and adults without DD, adults with DD who also have a mental illness or addiction disorder were found to have higher use of services (i.e., use of any physician services, emergency department (ED) visits, hospitalizations). They were also more likely to have repeat hospitalizations and visits to the ED within 30 days of leaving hospital or ED.

Discussion of findings

Town Hall participants' experiences and expectations were consistent with the overall finding that the presence of a mental illness or addiction disorder among individuals with DD is associated with even poorer health and more frequent health care access.

Regarding the higher prevalence of chronic health conditions among individuals with DD who have a mental illness and addiction disorder, some participants speculated whether these health conditions are being missed by general practitioners (GPs)

[3] The term addiction here and throughout refers to substance-related and addictive disorders. Non-substance related addictions (e.g., gambling, behavioral) were not always recorded reliably in the data used but were included where possible.

whose focus and time may be spent on addressing presenting mental health issues and so they are not screening for common chronic conditions.

Regarding the high rates of mental illness in adults with DD, one participant raised whether this be explained, at least in part, by the tendency of ED and hospital staff to diagnose individuals displaying behaviours typical of DD as a mental illness in order to more quickly access services. This tendency could not only inflate the estimated prevalence of mental illness in this population, but could also mean that specific types of DD, particularly autism, are under-detected and misdiagnosed as psychiatric in these health care settings.

> *"If you are a parent of an adult with DD, how do you find out about what is available? I am scrambling around to find things. Nobody is coming to me and saying, "Here is something that might help you." I have to go find it myself. Talk about burnout…"*

Discussion: What has worked well to prevent repeat ED visits and/or hospitalizations?

Participants were asked to discuss specifically what has worked well to prevent repeat ED visits or repeat hospitalizations. However, their answers focused more on what was needed vs. providing specific examples of effective solutions. Many participants argued that **improved access to a range of appropriate services, supports and staffing in the community** (e.g., health, mental health, social services, education) would prevent repeat ED visits and hospitalizations. Improved access would mean that emerging issues, including mental health and addiction problems, could be addressed before they develop into actual disorders and/or crises. Participants emphasized the importance of community services being available locally, having accessible hours of operation and coming with a point person to help individuals with DD and their families navigate through the system. Participants also emphasized that services should extend to families and caregivers who often experience significant burden and strain when trying to provide care in the absence of appropriate resources and support.

Participants also emphasized the important role that **primary health care** plays in managing and coordinating the health care of individuals with DD. GPs were felt to be in a position to not only detect the presence of both DD (including autism) and mental

health issues in their patients early, but to screen for common health care problems in this population, ideally during **annual comprehensive physical examinations**.

The **need for training for a range of health and social service providers** was also commonly highlighted. Hospital, ED and primary health care staff need increased capacity to better identify and manage behavioural and psychosocial issues among individuals with DD, and should have adequate knowledge to refer to appropriate community services. One participant emphasized that this training should ideally occur as part of their professional education, which was suspected to be largely absent in current curricula. The need to enhance training in special education for teachers and other support staff was also emphasized in order to better equip schools to support individuals with DD.

Finally, participants suggested that **the use of support/care plans** would ensure that care planning is proactive, is broadly shared and includes protocols to manage crises. Participants cautioned that care plans need to be current in order to be useful and must come with mechanisms to ensure that the entire **circle of care**, including family physicians, community service providers, educators and caregivers/supports, are aware of the needs and preferences of the individual with DD for care and support.

A CLOSER LOOK AT ADULTS WITH DEVELOPMENTAL DISABILITIES AND ADDICTION DISORDER

Key research findings

Among adults with DD who have either a mental illness or addiction disorder, most had a mental illness diagnosis. Those with an addiction disorder, while they were small in number (~13%), showed clear evidence of disproportionately higher need. They were more likely to be male and live in the poorest neighbourhoods. They were also more likely to have chronic obstructive pulmonary disease (COPD) and asthma, compared to adults with DD who had only a mental illness.

In terms of service use, adults with DD who had both a mental illness and addiction disorder had higher rates of both visits and repeat visits to the EDs and hospitals, as compared to adults with DD who had only a mental illness or only an addiction disorder.

"I was diagnosed at age 65 [with autism]. My whole life I didn't know and it was a huge breakthrough. There was a community to connect with, but mostly self-advocates - not so many providers, and I am a big part of it. I also suffered from depression and alcoholism. If had been diagnosed earlier, would my life have been different? Maybe I would have had better supports and wouldn't have self-medicated. I think what needs to happen is that physicians need to get better at diagnosing autism. Right now, only people with deep pockets who can afford psychologists get diagnosed so we are probably missing a huge group with autism."

Discussion of findings

Several Town Hall participants reported being surprised by the rate of addiction in adults with DD, even though the rate is relatively small in proportion to rates of mental illness. Some suggested that this surprise may be an indication that addiction may not be sufficiently on the radar of people concerned about the health and health care of adults with DD. It was also noted that the rate of addiction may be an underestimate since the health status of individuals with DD involved in the criminal justice system are

not necessarily reflected in the data. Some participants were also surprised by the lower rates of addiction reported for women with DD, compared to men with DD. One participant highlighted that women with DD are particularly vulnerable to abuse and trauma, both of which are associated with substance use in women. It may be that addiction is under-recognized in women and that disorder rates may actually be higher than reported.

Participants discussed the potential reasons for addiction disorders among adults with DD, including their marginalization in society (e.g., poorer living conditions increasing exposure to substances), the relief from suffering that substances offer in the absence of more appropriate services and supports (i.e., self-medication), and little to no access to addiction services and supports. Participants highlighted that individuals with mild DD may be particularly vulnerable to addiction because their disabilities are either not recognized or are not severe enough to qualify for already scarce services and supports. As a result, these individuals, described as "invisible" and "living in a high functioning hell", are at even greater risk of marginalization and may be more likely to self-medicate and/or to develop mental health issues in the absence of support. One participant noted that youth with mild disabilities, particularly those with disabilities resulting from Fetal Alcohol Spectrum Disorder (FASD), are not well supported in the school system and are often lost to the street or the criminal justice system by their late high school years. Participants discussed how supporting individuals with mild DD is particularly challenging as it requires an ethical balance between respecting their need and ability to live independently and protecting them from decisions that could harm their health and/or expose them to unsafe situations.

> "If you have a mild disability that is not recognized, you often don't get the services you need and end up living in as shelter or some other form of marginalized housing. In these settings you may be more exposed to substances which may, in turn, lead to addiction."
>
> "We have to address addictions issues among individuals involved in the justice system – there is currently no planning to support their transition back into the community."

Participants also discussed the finding that adults with DD and addiction disorders have higher rates of COPD and asthma. Suggestions regarding why this might be included higher rates of smoking in this group and increased exposure to poor air quality and environmental toxins resulting from marginalization and poor living conditions.

Discussion: What is needed to address the needs of individuals with an addiction disorder or the combination of a mental illness and addiction disorder?

Participants emphasized the need for increased access to integrated, appropriate and affordable mental health and addiction programming. Strategies to achieve this included:

- Increasing the capacity of psychiatric and other specialized services to address issues of addiction
- Developing mechanisms for collaboration and cross-training to build capacity in community services to address mental illness and addiction issues
- Providing a single point of access
- Ensuring adequate transition supports for individuals involved in the justice system
- Ensuring that a multi-disciplinary team is planning and coordinating care
- Increasing the awareness of service providers, individuals with DD and their families about existing community resources
- Address the link between low socio-economic status and mental illness and addiction disorders by increasing access to high quality, supportive housing and healthy recreational and social opportunities
- Expand efforts for cross-ministerial collaboration to better share data/resources and to enhance communities' response to the needs of individuals with DD

> "We need programs for addictions that are accessible. This may mean partnerships with addictions agencies and programs that provide mental health service to individuals with developmental disabilities – there needs to be capacity building on both sides."

SUGGESTIONS FOR FUTURE RESEARCH

Participants provided the following suggestions for future research that would enhance our understanding of the health and health service use of adults with DD who have mental illness or addiction disorders:

- Perceptions of care of individuals with mental illness or addiction disorders, including what worked, what didn't, and what was missing
- Rates of follow-up for chronic conditions
- How the health and health care of individuals varies by:
    - Gender – e.g., are the differing rates of mental illness and addiction disorders among men and women a reflection of true prevalence or current methods of detection? How might social differences or the ways in which health care is delivered impact rates of mental illness and addiction?
    - Level of disability –e.g., are individuals with mild disabilities fully represented in health and health care data? Does the level of disability impact the risk of mental illness and addiction disorders and access to health care services?
    - Type of diagnosis –e.g., is there a tendency to miss/misinterpret signs autism in certain health care settings, like hospitals and EDs?
- The extent to which issues impacting mental illness and addiction, including access to appropriate services, are a function of DD or are more broadly applicable to the general population (e.g., socioeconomic factors, gender)
- Health and health care access for individuals with DD involved in the justice system
- Evaluation of the impact of initiatives designed to better address the needs of individuals with DD, including those with mental illness or addiction issues
- Trends over time in the detection of DD, mental illness and addiction disorders, and access to health care

> "The best source of information is from the young adults with DD who went through the system - ask them about the mistakes that were made. Ask the kids that went through the system and survived. The information from them is invaluable."

The researchers would like to thank everybody who attended this Town Hall for their interest and their input. The ideas discussed provided valuable insights into the results observed from the analysis. These will be considered very carefully in preparing recommendations from this work.

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 the 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. Hélène Ouellette-Kuntz and Ms. Katherine McKenzie
February 19, 2015 - 1:00 – 3:00 pm
To access the video of the 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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