



Health Care Access Research
and Developmental Disabilities

HEALTHCARE ACCESS RESEARCH AND
DEVELOPMENTAL DISABILITIES
(H-CARDD)

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

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

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. Youth and young adults with DD encounter particular challenges as they transition into, and try to navigate, the adult health care system.

In December 2014, researchers leading the study of transition age youth with DD in Ontario hosted an interactive Town Hall to discuss findings about:

- Health service use patterns of youth with DD over the years they transition into the adult services system
- How young adults with Autism Spectrum Disorder (ASD) differ in their health and service use compared to others without ASD

This free and interactive Town Hall was broadcasted through the Ontario Telemedicine Network (OTN) and involved participants at over 38 OTN sites and an additional 68 participants joining by live Webcast.

TRANSITION AGE YOUTH WITH DEVELOPMENTAL DISABILITIES IN ONTARIO: HEALTH AND HEALTH SERVICE USE

Findings: Researchers first compared young adults with DD between 18 to 24 years of age from across Ontario to those in Ontario without DD. They found that individuals with DD are more likely to be male, their overall health is worse, and psychiatric diagnoses are more common. The researchers then looked back at how these young adults used healthcare services when they were younger, starting at ages of 14 and through to age 24. The researchers found that the likelihood of an individual with DD seeing family physicians or psychiatrists peaked around age 17 or 18, then declined to earlier levels. The likelihood of emergency department (ED) use and psychiatric hospitalizations also increases as individuals approached 17 to 18 years of age, but remained steady afterward.

Participants discussed reasons that might explain these patterns, including:

- A lack of readiness and support for **developmental and social milestones, such as increased identification with peers and transitions from school to community.**
- Need for supports to manage **the presence of difficult behaviours** that either emerge during the transition age years or that become more pronounced.
- The **absence/inaccessibility of community supports** that results in transition age youth and their families turning to more accessible health care services - often emergency care.
- **System requirements to access social and financial supports** that require recent assessment and/or diagnosis of DD from a health care professional.

A CLOSER LOOK AT YOUNG ADULTS WITH AUTISM SPECTRUM DISORDER (ASD)

Findings: Young adults with ASD in Ontario were compared to young adults with other developmental disabilities (DD) and to a comparison group of without DD. Young adults with ASD were more likely to be male compared to both those with other DDs, and to those with no DD. Psychiatric diagnoses were also found to be more common among young adults with ASD. Those with ASD and those with other DDs were equally less likely to see their family physician compared to those without DD. However, ED use was lower for those with ASD than for other individuals. When looking specifically at psychiatric emergencies and psychiatric hospitalizations, young adults with ASD were more likely to have these sorts of visits and to be admitted than peers without DD.

Participants discussed how the finding of increased risk for psychiatric diagnosis is consistent with mental health issues associated with ASD. They also speculated that rates of dual diagnosis may be underreported because behavioural problems are attributed to the ASD as opposed to a co-existing psychiatric disorder. Participants also suspected that ASD may be under-recognized and/or under-diagnosed in girls. Regarding service use, participants offered a number of suggestions to explain why young adults with ASD are less likely to visit the ED compared to both young adults without ASD and to young adults in general. These included barriers to communication and access, and fear of how challenging behaviours will be managed.

Participants offered a number of suggestions to help support transition age youth with DD. These included:

- Multi-sectoral and ministerial collaboration and coordination
- Development of transitions plans and related supports that:
 - are the responsibility of a dedicated service provider to implement
 - reflect contributions from a multi-disciplinary team
 - have protocols/processes for monitoring
- Life skill supports and opportunities for social connection
- Strategies to reduce barriers to services
- Early intervention/prevention
- Training and education for:
 - Families/Caregivers
 - Mental health service providers
 - Hospital and ED service providers
 - Family physicians
 - Community service providers
 - Peer supporters
 - Communities in general

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 transition age youth with DD:

- Study transitions in the education system and the roles that schools might play in supporting youth and young adults with DD through the transition years
- Rates of transition age youth with DD involved in criminal activity
- Comparing patterns of service use for transition age youth with DD with and without family doctors
- A closer look at potential differences in patterns of service use between male and female transition age youth with DD
- Patterns of substance use among transition age youth with DD

- Best practices in support transition age youth with DD as they transition from child to adult services and are living independently in the community
- Developing and implementing training for medical professionals

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 Developmental 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 study the health and health care of adults with DD in Ontario, beginning first with primary care.¹ Since 2013, H-CARDD has been further studying this cohort to gain a better understanding of issues related to specific subgroups of individuals with DD known to be particularly vulnerable. Transition age youth with DD constitutes one such group that may encounter difficulties as they move from pediatric services and begin to navigate the adult health care system. We know not getting timely care can make health problems for individuals with DD worse. We also know that adults with DD of all ages have higher rates of emergency room visits and psychiatric hospitalizations than those without disabilities.² There has, however, not been a lot of research specific to individuals transitioning to the adult system.

In December 2014, researchers leading the H-CARDD study of transition age youth with DD hosted an interactive Town Hall to present preliminary findings about:

- Health service use patterns for individuals with DD across the years spanning their 14th birthday (before the transition into adult services) and their 24th (after the transition); and

¹ See Lunskey 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 third chapter in Lunskey et al., (2013) for details.

- How young adults with Autism Spectrum Disorder (ASD) differ in their health and service use compared to others without ASD

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 in the different regions of Ontario and about what recommendations should flow from this research in order to improve the health and health care access of transition age youth with DD. This report provides a summary of the Town Hall proceedings, with a particular focus on the feedback and discussion shared 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/youth/town-hall-tay>

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 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 Town Hall was broadcast through the Ontario Telemedicine Network (OTN). Surrey Place Centre acted as the host site. 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.

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 and questions were posed directly to the presenters through OTN, through email, or through the webcast platform and were responded to live during the session.

Participants at 38 OTN sites participated in the Town Hall (some sites hosted more than one participant). In addition, 68 participants joined the Town Hall by live Webcast.

ABOUT THE PRESENTERS

Barry Isaacs is Director of Research, Evaluation and Education at Surrey Place Centre. He received his PhD in psychology from York University in 2004 and has been working in the field of developmental disabilities for over 20 years. His active research interests include health and healthcare for people with developmental disabilities, health and social service evaluation, quality of life for people with developmental disabilities and their families, and issues in medical education.

Jonathan Weiss (PhD, C. Psych) is an Associate Professor at York University and a Clinical Psychologist, who works with children, adolescents, and adults with developmental disabilities. He holds the Chair in Autism Spectrum Disorders Treatment and Care Research, funded by CIHR in partnership with Autism Speaks Canada, Health Canada, NeuroDevNet, the Sinneave Family Foundation, and CASDA.

Summary of Proceedings

TRANSITION AGE YOUTH AND YOUNG ADULTS WITH DEVELOPMENTAL DISABILITIES IN ONTARIO: HEALTH AND HEALTH SERVICE USE

Key research findings

Almost 16,000 youth with DD between 18 to 24 years of age from across Ontario were compared to approximately 393,000 youth without DD.

Transition age youth with DD differ from transition age youth without these disabilities in a few ways: they are more likely to be male (64% versus 50%), their overall health is worse (70% versus 52% with moderate to high morbidity), and psychiatric diagnoses are more common (43% versus 19%).

In terms of how they use services, transition age youth with DD are more likely to see their family physicians and psychiatrists as they age, with a peak around age 17 or 18. The likelihood of ED use and psychiatric hospitalizations also increases toward this age. Similar trends were not observed for transition age youth without DD.

Discussion: Factors contributing to service use patterns

The presenters highlighted that service use for transition age youth with DD generally increases from age 14, and either plateaus or levels off after ages 17 - 18. Participants discussed the factors that they felt contributed to these service use patterns.

Many participants discussed typical **developmental and social milestones** that youth during their transitional years are expected to reach – most notably increased identification with peers and transitions within and from school to community. For youth with DD, these transitions may be particularly difficult and may result in the need for increased support. For example, participants noted that youth with DD may have more difficulty establishing a positive, supportive peer network and managing the uncertainty of change, as they transition from elementary to high school and again from high school to the community. They must also leave behind long-time and familiar supports from teachers and staff as they leave high school—an expectation that some participants felt comes too early. One participant suggested that as transition age youth with DD work

through these difficulties, their need for increased support may lessen, thereby potentially explaining the plateau in service use after their high school years.

Some participants proposed that **the presence of difficult behaviours** may explain, at least in part, increased health service use during the transitional years. In some cases, families may seek supports when strategies that were used to manage difficult behaviours that started in childhood are no longer effective and/or appropriate for transition age youth with DD. In other cases, behaviours that were more benign in childhood may become increasingly problematic as youth reach the transition years. Still in other cases, difficult behaviours may only surface during the transition years due to normal developmental changes such as hormonal shifts, increased need for autonomy or increased risk taking in response to peer pressure.

In the **absence/inaccessibility of community supports**, participants noted that transition age youth with DD and their families are ill equipped to face the challenges noted above. As their ability to cope is diminished, (and problems may escalate to crises),

transition age youth with DD and their families are often forced to access whatever supports are available – typically from the health care sector, including emergency services. Some participants suggested that this gap is a result of needed infrastructure not keeping pace with the transition from institutional to community-based care.

Finally, participants discussed how **system requirements to access social and financial supports** may also result in increased health service use. For example, application requirements to access Ontario Disability Support Program (ODSP), Developmental Services Ontario (DSO) and adult respite services may require recent assessment and/or a diagnosis of DD from a health care professional.

“I think we see more health and mental health concerns at this age partly because youth begin to separate themselves into more selective groups moving forward into adulthood. These young people with DD are being left behind, [they] become more isolated in the community and are more vulnerable to abuse, injury and neglect. They too are looking for autonomy and may not have the supports and resources available to assist in a safe way.”

A CLOSER LOOK AT YOUNG ADULTS WITH AUTISM SPECTRUM DISORDER (ASD)

Key research findings

Over 5000 of the young adults discussed above were identified as having ASD. These individuals with ASD were compared a group of approximately 10,000 young adults with other developmental disabilities (DD) and to a group of approximately 393,000 young adults without DD.

Young adults with ASD were more likely to be male compared to both those with DD without ASD, and those with no DD (78% versus 58% and 50%). Psychiatric diagnoses were also found to be more common among transition age youth with ASD compared to the other two groups (51% versus 38% and 19%).

In terms of health service use, those with ASD and those with other DD were equally likely to see their family physician, and both were less likely to see their family physician compared to those without DD. However, ED use was lower for those with ASD than other individuals. When looking specifically at psychiatric emergencies and psychiatric hospitalizations, young adults with ASD were more likely to have these sorts of visits and be admitted compared to peers without DD.

“What’s happening is...a failure to connect not just in health care sectors, but in every sector of an individual’s life. Thus, a community of support needs to exist around each individual, where the team is comprised of all people involved with the progress of the individual.”

Discussion: Context for understanding patterns of health status and service use of young adults with DD

Regarding health status, participants generally reported that it makes intuitive sense that youth with ASD are at greatest risk for psychiatric diagnosis, largely because of the anxiety and obsessive behaviours associated with ASD. Some participants suspected, however, that psychiatric disorders are under diagnosed and that rates of dual disorders are actually higher. Potential reasons offered for under-diagnosis included

overshadowing of ASD behaviours (resulting in other disorders being overlooked) and psychiatric problems not being identified until youth are hospitalized. Participants also questioned the higher reported prevalence of ASD among young male adults as compared to young female adults, suspecting that ASD in girls is less likely to be recognized/diagnosed (e.g., “*girls tend to observe, imitate and pass as normal*”).

Regarding service use, participants offered a number of suggestions to explain why young adults with ASD are less likely to visit the ED compared to both young adults without ASD and to young adults in general. In addition to barriers to communication and access, the most common reason was fear of how challenging behaviours may be perceived/managed- a fear that may be reinforced by past negative experiences with hospital and emergency services.

Discussion: What is needed to support transition age youth with DD

Participants offered a number of suggestions to help support transition age youth with DD. A common theme in this feedback was the need for a comprehensive, coordinated and seamless continuum of supports:

- Multi-sectoral and ministerial collaboration and coordination - between for example, education, health, social services, mental health, child protection, and justice; participants voiced concerns that relevant ministries and sectors are currently too siloed and that more needs to be done to ensure a “community of support” for transition age youth with DD and their families/caregivers.
- Development of transitions plans and related supports which address major areas of life– for example: academic, health, mental health, social, vocational, etc. These plans should:
 - reflect contributions from a multi-disciplinary team, drawing from health, mental health, social service and education professions

- have protocols/processes for monitoring both current areas of concern and emerging issues that may benefit from early intervention (see also below)
- be the responsibility of a dedicated service provider to implement – some participants suggested a doctor (either family physician or psychiatrist) would be well positioned for this role but would require incentives (e.g., ability to bill) to provide this function
- Life skills supports and opportunities for social connection - As discussed earlier, young adults with DD reportedly experience significant stress and anxiety when there is pressure to transition away from school/families into the community before they are ready. Participants felt that a social network is particularly important during this period, as is a dedicated space that provides opportunities for transition age youth with DD to develop life and social skills in a supportive environment.

"We need continuity of care. We give a diagnosis and then parents are left to manage on their own. There should be suggestions given on when to seek help (either at certain developmental times or when specific behavioural indicators arise) so we have a chance at early intervention/prevention of future psychiatric problems. Like when picky eating changes to not eating in certain situations/environments - this is a social phobia that maybe grows out of attributes of the ASD."
- Strategies to reduce barriers to services – Transition age youth with DD and their families often encounter barriers that prevent them from accessing what services are available. A major barrier identified by a number of participants was funding – often families/caregivers must reportedly pay out of pocket for services like assessments and case management that are not covered by OHIP and social assistance. Practical supports, like access to transportation and education to families (see below) would also minimize barriers to accessing care.

- Early intervention/prevention – Several participants identified the need for more investment in early intervention/prevention services. This was felt to be particularly important to address the increased risk for mental illness among transition age youth with DD. Specific suggestions included interventions focusing on enhancing resiliency in youth and families/caregivers and social and emotional skill-building. And as was noted earlier, families and community service providers are felt to require more education and training to identify when emerging issues may require professional intervention.
- Training and education for:
 - Families/Caregivers – Participants noted the importance of education and training, particularly when children with DD are young and parents/caregivers are first learning strategies and supports that will prevent future health, mental health and social problems. Participants also highlighted that parents are also often left to determine on their own when emerging issues are “typical” - for example, when they reflect a particular DD diagnosis, or in the case of transition age youth, are a result of normal developmental changes. Proactive education and training will ensure that parents know when these emerging issues may require attention/intervention from a professional.
 - Mental health service providers – It was noted that transition age youth with DD and their families/caregivers are often excluded from children’s mental health services due to lack of capacity to address their unique needs. Even when these services are accessible, some participants were concerned that service providers do not have the necessary training/education to provide appropriate care.
 - Hospital and ED service providers – Participants identified the need for education in EDs and other areas of the hospital that may be called upon to provide care to transition age youth with DD in crises. Capacity building should include training and education to staff, to develop their clinical skills, and to managers/administrators, to ensure that the physical environment has the necessary supports to meet the unique needs of transition age youth with DD (e.g., access to quiet rooms, communication supports, etc.).

- Family physicians – Participants noted that few family physicians have sufficient training and comfort to work with patients with developmental differences and those few who do are difficult to find. This is particularly problematic given the increased vulnerability to health problems among individuals with DD.
- Community service providers – Several participants identified gaps in a range of community services (e.g., education, health, mental health, etc.), particularly in jurisdictions more removed from urban centres. There was also concern that a lack of education and training can result in the provision of services that are uninformed, inappropriate or even harmful, or in a failure to identify emerging issues that may require attention.

“This is a community issue – not just an agency or family issue – the community needs to redefine what “Normal Community” means...it means folks with disabilities are part of it.”
- Peer supporters – One participant highlighted that peer supporters are a largely untapped resource that could help fill in service gaps. Building capacity in peer supporters would also provide the added benefit of creating important vocational opportunities for adults with DD.
- Communities in general - Participants identified the need for community education regarding the needs of people with DD with the larger goal of promoting their inclusion in the community.

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 transition age youth with DD:

- Study transitions in the education system and the roles that schools might play in supporting youth and young adults with DD through the transition years
- Rates of transition age youth with DD involved in criminal activity
- Comparing patterns of service use for transition age youth with DD with and without family doctors
- A closer look at potential differences in patterns of service use between male and female transition age youth with DD
- Patterns of substance use among transition age youth with DD
- Best practices in support transition age youth with DD as they transition from child to adult services and are living independently in the community
- Developing and implementing training for medical professionals

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. 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>

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