



Bridging gaps between research and practice in the primary care of adults living with intellectual and developmental disabilities
Surrey Place Centre launches new program developing resources and tools for primary care providers

For Immediate Release

May 1, 2018, Toronto –Research involving adults living with intellectual and developmental disabilities (IDD) reveals gaps between their health needs and the primary care they often receive. These gaps can lead to hospitalization and repeat emergency department visits. Appropriate and timely primary care can prevent physical and mental health conditions from developing or becoming more severe, and offer continuity of care and a more person-centred health care experience.

It is important that family physicians and other primary care providers have access to information about how to adapt health care to the specific needs of adults living with IDD. Navigating health care can be challenging for young adults with IDD who are transitioning from pediatric care to an adult healthcare system that is less oriented to their needs. Increased training and education of primary care providers in identifying physical and mental health needs and in proactive transition planning enable them to play an important role in these transitions.

Adults with IDD should receive primary care that meets their specific health and developmental needs. Surrey Place Centre is committed to bridging the gaps between research and practice in primary care for adults with IDD and as a result has launched a new program that develops, publishes and promotes clinical practice guidelines, tools and other resources for primary care providers. The Developmental Disabilities Primary Care Program, funded by the Ontario Ministry of Health and Long-Term Care and the Ministry of Community and Social Services, will serve as a credible online resource for primary care providers.

The launch of this program coincides with the publication of the [*Primary care of adults with intellectual and developmental disabilities: Canadian consensus guidelines*](#) in the April 2018 issue of the *Canadian Family Physician* journal. These guidelines offer important background regarding specific physical and mental health care needs of adults with IDD and recommendations for patient and caregiver-centred approaches to care; preventative care assessments; and interventions. The guideline recommendations are based on recent Canadian population-based data, empirical research, clinical knowledge, as well as knowledge of the contexts of care of adults with IDD. Moreover, the experience of adults with IDD and their caregivers was also included in developing the recommendations.

Developing and disseminating online resources for family physicians will help them to care for adults living with IDD and meet their physical and mental health care needs. However, improving care will require addressing further gaps in research, developing more practice tools and enhancing the education and awareness of IDD in the health professional curricula such as medicine, nursing, social work and other allied health professionals. The Developmental Disabilities Primary Care Program of Surrey Place Centre will continue to bridge the gaps between clinical guidelines and practice.

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Quotations:

Mr. Steven Finlay: "At Surrey Place Centre we serve infants, children, youth and adults with developmental disabilities, including children and youth living with autism spectrum disorders. We recognize the need to improve the health services provided to youth and adults with developmental disabilities and are pleased to have launched a new program that addresses this need. We are committed to improving best practices through research and education, not only for the benefit and wellbeing of our clients throughout their life-span, but for all adults with intellectual and developmental disabilities seeking health care services."

Steven Finlay, MSW, RSW
Chief Executive Officer, Surrey Place Centre

Dr. Terri Hewitt: "We need to be reminded that as children age out of children and youth services they will experience major changes in the services they receive as adults because they will be transitioning from a specialized and comprehensive pediatric system to general family physician and other primary care practices. As a result, we need to support family physicians with resources, guidelines and tools that facilitate planning and coordinating care during these transitions. The Surrey Place Centre Developmental Disabilities Primary Care Program will serve as a centre for online information."

Terri Hewitt, PhD C.Psych.
Vice President of Developmental Services, Surrey Place Centre

Dr. William F. Sullivan: "As a family physician caring for patients with intellectual and developmental disabilities, I have seen a growing need for basic health care guidance for primary care providers on what is different about the care for adults with IDD. Working closely with physicians who have clinical expertise in caring for adults with IDD, we developed recommendations in three sections; general approaches to care, physical health and mental health care. These guidelines are unique in that we considered different types of knowledge, including the experience of health care for patients and caregivers."

William, F. Sullivan, MD, CCFP (COE), FCFP, PhD
Developmental Disabilities Primary Care Program Lead, Surrey Place Centre
Academic Family Health Team, Dept. of Family and Community Medicine, St Michael's Hospital

Dr. Trevor Young: "Our medical education programs at all levels increasingly rely on the clinical practice guidelines and other resources from the Developmental Disabilities Primary Care Program at Surrey Place Centre. The recent updates to this program will keep our curricula current and let us continue to train a physician population that is aware of — and able to address — the specialized health needs of people with developmental disabilities."

Trevor Young, MD, PhD, FRCPC, FCAHS
Dean, Faculty of Medicine and Vice Provost, Relations with Health Care Institutions, University of Toronto



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About Surrey Place Centre

Surrey Place Centre provides specialized clinical services that are responsive to individual needs and help promote health and well-being. In addition to the direct service role, the Centre facilitates system-wide access to information and supports. As an organization we are committed to supporting the social inclusion of people with developmental disabilities, autism spectrum disorder, as well as young children challenged with visual impairments. For more information visit www.surreyplace.on.ca.

About Developmental Disabilities Primary Care Program

The Developmental Disabilities Primary Care Program develops, publishes and promotes clinical practice guidelines for primary care that are informed by ethics, empirical studies, expert knowledge, current research on health care systems and other contexts of care, including the perspectives and experiences of adults with intellectual and developmental disabilities and their caregivers.

Quick Facts:

- Adults with intellectual and developmental disabilities (IDD) have poorer health, and more complex health issues, than other adults. They have higher rates of chronic diseases, such as diabetes, congestive heart failure, and asthma.
- Nearly 1 in 2 adults with IDD are given a mental illness or addiction diagnosis at some point in their lives. The guidelines promote a systematic assessment of mental health and behaviours that challenge.
- Approximately 1 in 5 adults with IDD receive a guideline recommended periodic comprehensive health assessment. The guidelines emphasize periodic preventive health assessments and developing integrated health action plans. These guidelines provide a step-by-step approach and links to tools for preventive care assessments that are adapted for adults with IDD.
- Adults with IDD are just as likely to see their family physician as other adults; however, they are more likely to visit emergency departments and to be hospitalized for preventable primary care issues.
- Interprofessional health care is recommended for adults with IDD; however, a 2013 report indicated that only 20% receive their care from interprofessional family health teams.
- Developmental Disabilities Primary Care Program of Surrey Place Centre is working closely with primary care providers to develop clinical practice tools and resources for IDD primary care, which will be released in the October of 2018.



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Additional Resources:

- Practice tools and an online version of the guidelines are available at the Developmental Disabilities Primary Care Program, Surrey Place Centre website: www.surreyplace.ca/ddprimarycare
- The research facts in this communication are based on Canadian population-based research by the Health Care Access Research and Developmental Disabilities (H-CARDD) program. Visit www.hcardd.ca for more information and research publications on the health status and health services use of adults with intellectual and developmental disabilities in Ontario.
- A complementary April 2018 special issue on the primary care of adults with intellectual and developmental disabilities is now available online by the *Canadian Family Physician* at www.cfp.ca. This special issue includes articles, mainly authored by family physicians from across Canada, that elaborate on the primary care guidelines, with a focus on youth and young adults with IDD transitioning into adulthood.

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