

# A greater understanding

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*We are not called by God to do extraordinary things, but to do ordinary things with extraordinary love.*

Jean Vanier

One of the most challenging experiences of my family practice residency was looking after Mary and her partner, James. Both had substantial intellectual disabilities, were deaf, and had mobility problems such that they required mobility scooters to get about, including to medical appointments. I often felt overwhelmed when seeing them, as I struggled with the many challenges of being their family physician—creating the space in the office to be able to physically accommodate them, communicating with them, and last, but by no means least, addressing their acute and preventive health care needs. In the early 1990s, training family medicine residents to care for people like Mary and James after graduation and into practice was not really on anyone's radar.

Although people with intellectual and developmental disabilities (IDD) make up 1% to 3% of the Canadian population and have physical and mental health problems that are both preventable and manageable,<sup>1</sup> until recently the health status of and health care received by those with IDD was not much researched.<sup>2</sup> Not surprisingly, there is evidence that there are many gaps in the care of adults with IDD and that to improve such care, better supporting primary care providers, including family physicians, is a key component.<sup>2</sup>

To that end, in 2006 *Canadian Family Physician* published the very first "Consensus guidelines for primary care of adults with developmental disabilities"<sup>3</sup> and updated them in 2011.<sup>4</sup> As Sullivan and colleagues point out in their thoughtful commentary (page S5),<sup>1</sup> these guidelines drew attention to the health disparities that adults with IDD face and provided useful, practical support to family physicians to help address these disparities. In the April issue of the journal, *Canadian Family Physician* is pleased to publish an updated version of the guidelines,<sup>5</sup> along with valuable clinical and research content in this companion special issue that will further contribute to improving care for those with IDD in Canada and beyond.<sup>6</sup>

This special issue includes important content on what people with IDD say they want and need in their care (page S8).<sup>7</sup> It also includes a practical clinical review (page S23)<sup>8</sup> that will provide family physicians with a greater understanding that behaviours that challenge in people with IDD might be a sign of a change in health status or even serious illness.

As with all our patients, some of the greatest vulnerabilities that people with IDD face is in life-stage transitions—from childhood to adolescence, from adolescence to adulthood, from adulthood to late life, and from late life to end of life. Helpful guidance on improving the transition to adulthood is provided in a clinical review by Ally and colleagues (page S37).<sup>9</sup>

As generalists who are used to managing complexity and uncertainty, family physicians are ideally situated to provide care to people with IDD in all their complexity (page S15),<sup>10</sup> but resources and supports are required to assist us in providing high-quality care. *Canadian Family Physician* is proud to publish the updated 2018 guidelines,<sup>5</sup> as well as the first-ever special issue of the journal,<sup>6</sup> on this important and, until recently, neglected area of practice. We hope that readers will find it of great value. 🌟

## References

- Sullivan WF, Heng J, Salvador-Carulla L, Lukersmith S, Casson I. Approaches to primary care of adults with intellectual and developmental disabilities. Importance of frameworks for guidelines. *Can Fam Physician* 2018;64(Suppl 2):S5-7.
- Lunsky Y, Balogh RS, Cobigo V, Isaacs B, Lin E, Ouellette-Kuntz HMJ. Primary care of adults with developmental disabilities in Ontario. *Healthc Q* 2014;17:11-3.
- Sullivan WF, Heng J, Cameron D, Lunsky Y, Cheetham T, Hennen B, et al. Consensus guidelines for primary health care of adults with developmental disabilities. *Can Fam Physician* 2006;52:1410-8. Erratum in: *Can Fam Physician* 2007;53:31.
- Sullivan WF, Berg JM, Bradley E, Cheetham T, Denton R, Heng J, et al. Primary care of adults with developmental disabilities. Canadian consensus guidelines. *Can Fam Physician* 2011;57:541-53 (Eng), e154-68 (Fr).
- Sullivan WF, Diepstra H, Heng J, Ally S, Bradley E, Casson I, et al. Primary care of adults with intellectual and developmental disabilities. 2018 Canadian consensus guidelines. *Can Fam Physician* 2018;64:254-79 (Eng), e137-66 (Fr).
- Sullivan WF, editor. Special issue on primary care of adults with intellectual and developmental disabilities. *Can Fam Physician* 2018;64(Suppl 2):S1-78.
- Boyd K, Diepstra H, Elbard K, Hamdani Y, Lunsky Y. Consumer inclusion. Experience of patients with intellectual and developmental disabilities informs primary care. *Can Fam Physician* 2018;64(Suppl 2):S8-11.
- Green L, McNeil K, Korossy M, Boyd K, Grier E, Ketchell M, et al. HELP for behaviours that challenge in adults with intellectual and developmental disabilities. *Can Fam Physician* 2018;64(Suppl 2):S23-31.
- Ally S, Boyd K, Abells D, Amaria K, Hamdani Y, Loh A, et al. Improving transition to adulthood for adolescents with intellectual and developmental disabilities. Proactive developmental and systems perspective. *Can Fam Physician* 2018;64(Suppl 2):S37-43.
- Grier E, Abells D, Casson I, Gemmill M, Ladouceur J, Lepp A, et al. Managing complexity in care of patients with intellectual and developmental disabilities. Natural fit for the family physician as an expert generalist. *Can Fam Physician* 2018;64(Suppl 2):S15-22.

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