

# Approaches to primary care of adults with intellectual and developmental disabilities

## Importance of frameworks for guidelines

William F. Sullivan MD CCFP(COE) FCFP PhD John Heng MA

Luis Salvador-Carulla MD PhD Sue Lukersmith PhD MErg Ian Casson MD MSc FCFP

People with intellectual and developmental disabilities (IDD), or *intellectual disability (intellectual developmental disorder)* in the *Diagnostic and Statistical Manual of Mental Disorders*, 5th edition,<sup>1</sup> make up 1% to 3% of the Canadian population and are encountered in most family medicine practices.<sup>2</sup> Research in Ontario shows that they visit family physicians and enjoy similar continuity of primary care as patients without IDD.<sup>3</sup> Yet they have been called the “invisible 3%” in health care.<sup>2</sup> They are more likely to live in poverty, have higher rates of visits to emergency departments and stays in hospitals, and receive lower rates of preventive care screening compared with those without such disabilities.<sup>2,4,5</sup>

People with IDD have general health care needs like the rest of the population. They might have comorbid or secondary physical and mental health conditions that are preventable or that can be well managed. The manifestations of distress and illness in people with IDD can vary from those typically encountered by family physicians. For example, symptoms of reflux esophagitis might present as a change in behaviour. There can also be compounding factors affecting their health and functioning. For example, antiepileptic medication might decrease cognitive abilities. Family physicians might need to adjust their approaches to communication, assessment, and intervention to care appropriately for people with IDD. Research shows that physicians can gain confidence and improve such care as they become knowledgeable regarding the unique health needs and challenges faced by this group of patients.<sup>6,7</sup>

One recommendation of the *World Report on Disability* was to develop person-centred, evidence-based guidelines for assessing and treating people with disabilities, a vulnerable group in society.<sup>8</sup> Such guidelines can be useful for identifying specific health needs and challenges, assisting the decision making of family physicians with their patients with IDD and their caregivers, providing the knowledge base for training family physicians and other health care professionals, and highlighting gaps in research for further investigation. In advancing knowledge, such as developing guidelines, Salvador-Carulla and others have proposed that “framing of scientific knowledge” (which this article refers to as *adoption of a framework*) is a distinct type of research methodology that is essential in areas of health care in which there are high levels of variability, complexity, and uncertainty.<sup>9</sup>

Such frameworks are explicit principles that are derived by a consensus of experts in a field to aid interpretation and evaluation of data derived from empirical, observational, and other studies. They have a valid basis in the clinical experience and knowledge of these experts.

### Health disparities framework

In 2006, *Canadian Family Physician* published “Consensus guidelines for primary health care of adults with developmental disabilities” (hereafter referred to as *the guidelines*).<sup>10</sup> These guidelines drew attention to the reality that adults with IDD have a high risk of poor health and premature death owing in part to health disparities unique to adults with IDD.<sup>11,12</sup> The 2006 guidelines, and their revision in 2011,<sup>13</sup> sought to increase primary care providers’ capacity to identify these disparities and address them through preventive and other health care interventions.

The health disparities framework adopted by the 2006 and 2011 guidelines is based on the ethical principle that health care is a fundamental human right and that access by all to the highest standard of health care possible in their community is part of the common good. Hence, addressing health disparities unique to adults with IDD is a matter of good medical practice and social justice. These principles have been affirmed by the United Nations’ Convention on the Rights of Persons with Disabilities, which the federal government of Canada ratified on March 10, 2011, with agreement by every province and territory. Article 25 of the Convention stipulates that people with disabilities have the “right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability.”<sup>14</sup> States are obligated to provide health care that people with disabilities need “specifically because of their disabilities.”<sup>14</sup> Health care professionals have the responsibility to provide care of the same quality to people with disabilities as to others and to fulfil that responsibility through “training and the promulgation of ethical standards.”<sup>14</sup> Hubert H. Humphrey has said that

the moral test of government is how that government treats those who are in the dawn of life, the children; those who are in the twilight of life, the elderly; those who are in the shadows of life, the sick, the needy and the handicapped.<sup>15</sup>

These words apply not only to governments but also to those involved in the provision of health care.

### Health complexity framework

The revised 2018 guidelines published in *Canadian Family Physician*,<sup>16</sup> together with this special issue of articles on certain recommendations,<sup>17</sup> are also shaped by a health complexity framework. This approach involves accounting for multiple, interacting, and often compounding factors that influence the health and functioning of people with IDD. These factors include their health characteristics, environments, communication challenges, systems of health care, and social supports. In providing primary care to adults with IDD, family physicians often make decisions under conditions in which there are high levels of uncertainty<sup>18</sup> and ambiguity.<sup>19</sup> To make the best possible decisions under such conditions, family physicians need knowledge derived from research on a patient's local context and from the practical wisdom of experienced clinician experts.<sup>20</sup> Family physicians also need to understand the preferences and values of patients and their caregivers to deliberate with them regarding intervention options that are appropriate for the circumstances of these patients and that are acceptable to them. These distinct types of knowledge form a basis for each of the 2018 guideline recommendations just as each type of knowledge addresses a different basis for clinical decisions in complex health care.<sup>21</sup>

### Relational and person-centred care framework

The 2006, 2011, and 2018 guidelines, and the articles in this special issue, all adopt a relational and person-centred care framework in forming recommendations.<sup>22</sup> In the 2018 guidelines, this framework is made explicit in the new section on approaches to care, which begins with a guideline on person-centred care (guideline 1).<sup>16</sup> This approach is defined as one in which health care relationships put the person with IDD

at the centre of communication, planning, and decisions regarding care. This might require more time than that allocated to the typical office visit, getting to know the patient as a person and the patient's community, and engaging additional supports.<sup>16</sup>

The important concepts here are the relational aspect of health care and the central place of the person with IDD. These concepts are evident, for example, in the revised guideline on decision making (guideline 3).<sup>16</sup> This guideline highlights supported and shared decision making as a way for adults with IDD to contribute optimally to decisions affecting their health care with the support of their family physicians and trusted caregivers. This approach to health care decision making might also avoid the need for legal appointment of others to make decisions on behalf of a patient who is assessed to lack


some aspect of decision-making capacity (eg, a guardian who might not know such a patient well).

The relational and person-centred care framework also shapes the guideline on behaviours that challenge (guideline 27).<sup>16</sup> Such behaviour often emerges from an interaction between a person with unique needs and his or her environment. They might signal the absence of necessary environmental accommodations or insufficient supports. Behaviours that challenge can be the way a person with IDD communicates distress.<sup>23</sup> Guideline 27 presents a comprehensive and systematic approach by which family physicians and others can assess the causes (which might be multiple) of a person with IDD's distress.<sup>16</sup>

The relational and person-centred care framework of the 2018 guidelines also shapes a new guideline regarding life transitions (guideline 12).<sup>16</sup> These are life phases during which people with IDD require different or greater supports, such as during their transitions to adolescence, adulthood, frailty, and the end of life. People with IDD can develop decision-making, coping, and other life skills for these transitions with the support of others. Continuity in core relationships in health care, and a coordinated care plan for moving toward different and new supports, can minimize the distress of people with IDD and their caregivers and provide beneficial support during these important periods of change in their lives.

Because people with IDD benefit especially from holistic, biopsychosocial approaches to health care and from support from others for their developmental and caregiving needs, integration of their primary health care should cover the various health and allied health care specialties that are engaged, as well as their network of supports.<sup>24</sup> Family physicians play a key role in this integration as the central hub for the timely provision and coordination of all physical and mental health care needs of adults with IDD. They also provide a stable and core health care relationship on which these patients, their families, and other caregivers can rely. The objectives of the Patient's Medical Home model that the College of Family Physicians of Canada has articulated<sup>25</sup> can be used in conjunction with the 2018 guidelines as standards for relational and person-centred primary care of adults with IDD.

### Conclusion

Frameworks are a type of knowledge that can inform the development of guidelines. By applying health disparity, health complexity, and relational and person-centred care frameworks, the 2018 guidelines and this special issue of related articles both provide practical recommendations regarding beneficial assessments and interventions and also help to orient and shape the practices of family physicians. The principles that form these frameworks are applicable not only to developing guidelines for primary care of adults with IDD, but also those for primary care of other groups who are vulnerable in society and have similar needs. 

**Dr Sullivan** is Associate Professor in the Department of Family and Community Medicine at the University of Toronto in Ontario, a staff physician in Medical Services at Surrey Place Centre and the Family Practice Unit at St Michael's Hospital, and Director of the Developmental Disabilities Primary Care Program at Surrey Place Centre. **Mr Heng** is Assistant Professor in the Department of Philosophy and the Department of Interdisciplinary Studies at King's University College in London, Ont. **Dr Salvador-Carulla** is Professor in and Head of the Centre for Mental Health Research at the Research School of Population Health at Australian National University in Canberra. **Dr Lukersmith** is a research affiliate in the Centre for Disability Research and Policy at the University of Sydney in Australia. **Dr Casson** is Associate Professor in the Department of Family Medicine at Queen's University in Kingston, Ont.

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None declared

#### Correspondence

**Dr William F. Sullivan**; e-mail [bill.sullivan@utoronto.ca](mailto:bill.sullivan@utoronto.ca)

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#### References

- American Psychiatric Association. *Diagnostic and statistical manual of mental disorders*. 5th ed. Washington, DC: American Psychiatric Association; 2013.
- Lennox N. Following treatment guidelines for developmentally disabled adults. The invisible 3%. *Can Fam Physician* 2006;52:1373-4.
- Isaacs BJ, Jaakkimainen RL, Barnsley J, Klein-Gethink JE, Balogh RS, Cobigo V, et al. Health services utilization. In: Lunskey Y, Klein-Geltink JE, Yates EA, editors. *Atlas on the primary care of adults with developmental disabilities in Ontario*. Toronto, ON: Centre for Addiction and Mental Health, Institute for Clinical Evaluative Sciences; 2013.
- Cameron C. *Looking into poverty: income sources of poor people with disabilities in Canada*. Toronto, ON: Institute for Research and Development on Inclusion and Society; 2012.
- Ouellette-Kuntz HMJ, Cobigo V, Balogh RS, Wilton AS, Lunskey Y. Secondary prevention. In: Lunskey Y, Klein-Geltink JE, Yates EA, editors. *Atlas on the primary care of adults with developmental disabilities in Ontario*. Toronto, ON: Centre for Addiction and Mental Health, Institute for Clinical Evaluative Sciences; 2013.
- Bartkowski JP, Kohler J, Escude CL, Xu X, Bartkowski S. Evaluating the impact of a clinician improvement program for treating patients with intellectual and developmental disabilities: the challenging case of Mississippi. *Healthcare (Base)* 2018;6(1):piiE3.
- Balogh R, Wood J, Lunskey Y, Isaacs B, Ouellette-Kuntz H, Sullivan W. Care of adults with developmental disabilities. Effects of a continuing education course for primary care providers. *Can Fam Physician* 2015;61:e316-23. Available from: [www.cfp.ca/content/cfp/61/7/e316.full.pdf](http://www.cfp.ca/content/cfp/61/7/e316.full.pdf). Accessed 2018 Feb 25.
- World Health Organization, World Bank. *World report on disability*. Geneva, Switz: World Health Organization; 2011.
- Salvador-Carulla L, Fernandez A, Madden R, Lukersmith S, Colagiuri R, Torckar G, et al. Framing of scientific knowledge as a new category of health care research. *J Eval Clin Pract* 2014;20(6):1045-55.
- Sullivan WF, Heng J, Cameron D, Lunskey 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.
- Hosking FJ, Carey JM, Shah SM, Harris T, DeWilde S, Beighton C, et al. Mortality among adults with intellectual disability in England: comparisons with the general population. *Am J Public Health* 2016;106(8):1483-90. Epub 2016 Jun 16.
- Ouellette-Kuntz H, Shooshtari S, Balogh R, Martens P. Understanding information about mortality among people with intellectual and developmental disabilities in Canada. *J Appl Res Intellect Disabil* 2015;28(5):423-35.
- 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).
- Committee on the Rights of Persons with Disabilities. *Convention on the rights of persons with disabilities*. New York, NY: United Nations; 2006. Available from: [www.ohchr.org/EN/HRBodies/CRPD/Pages/ConventionRightsPersonsWithDisabilities.aspx](http://www.ohchr.org/EN/HRBodies/CRPD/Pages/ConventionRightsPersonsWithDisabilities.aspx). Accessed 2018 Feb 25.
- Humphrey HH. Remarks of Hubert H. Humphrey. Dedication of the Hubert H. Humphrey Hew Building. *Congressional Record* 1977;123:37287.
- 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.
- Sturmberg JP, O'Halloran DM, Martin CM. People at the centre of complex adaptive health systems reform. *Med J Australia* 2010;193(8):474-8.
- Salvador-Carulla L, Bertelli M, Martinez-Leal R. The road to 11th edition of the International Classification of Diseases: trajectories of scientific consensus and contested science in the classification of intellectual disability/intellectual developmental disorders. *Curr Opin Psychiatry* 2018;31(2):79-87.
- Salvador-Carulla L, Garcia-Alonso C, Gibert K, Vazquez-Bourgon J. Incorporating local information and prior expert knowledge to evidence-informed mental health system research. In: Thornicroft G, Ruggeri M, Goldberg D, editors. *Improving mental health care: the global challenge*. 1st ed. London, UK: John Wiley & Sons; 2013.
- Salvador-Carulla L, Lukersmith S, Sullivan W. From the EBM pyramid to the Greek temple: a new conceptual approach to guidelines as implementation tools in mental health. *Epidemiol Psychiatr Sci* 2017;26(2):105-114.
- Mezzich JE, Salloum IM, Cloninger CR, Salvador-Carulla L, Kirmayer LJ, Banzato CE, et al. Person-centred integrative diagnosis: conceptual bases and structural model. *Can J Psychiatry* 2010;55(11):701-8.
- Bradley E, Korossy M. HELP with behaviours that challenge. *J Dev Disabil* 2016;22(2):101-20.
- Bertelli MO, Salerno L, Rondini E, Salvador-Carulla L. Integrated care for people with intellectual disability. In: Amelung V, Stein V, Goodwin N, Balicer R, Nolte E, Suter E, editors. *Handbook integrated care*. Cham, Switz: Springer; 2017.
- College of Family Physicians of Canada. *A vision for Canada. Family practice. The Patient's Medical Home*. Mississauga, ON: College of Family Physicians of Canada; 2011. Available from: [www.cfpc.ca/A\\_Vision\\_for\\_Canada](http://www.cfpc.ca/A_Vision_for_Canada). Accessed 2018 Feb 25.

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