

Aging with intellectual and developmental disabilities

Family physicians can make a difference



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The friend of time doesn't spend all day saying: "I haven't got time." He doesn't fight with time. He accepts it and cherishes it.

Jean Vanier

This is the second of 2 special issues^{1,2} of *Canadian Family Physician* dedicated to deepening FPs' understanding of the health care needs and gaps in the care of persons with intellectual and developmental disabilities (IDD).

The first special issue, published in April 2018, focused on the health of adolescents and young adults with IDD and the role that FPs can play in their care and in advocating for better care.³ It was also accompanied, in the regular April issue, by a comprehensive, updated clinical practice guideline for primary care of adults with IDD.⁴ This second issue is dedicated to the care of persons aging with IDD.

Life expectancy in those with IDD has increased in the past few decades. Life expectancy for persons with mild IDD is nearly the same as that of the general population, and persons with moderate or severe IDD can now live into their late 60s and late 50s, respectively.⁵ Overall, however, the average lifespan of those with IDD remains substantially lower than in the general population.

Aging with IDD continues to present considerable challenges, as there is good evidence that while older persons with IDD experience the same age-related chronic diseases seen in the older general population, many of their health care needs go unidentified and unmet when compared with the general population.^{5,6} Persons aging with IDD experience unrecognized or poorly managed health conditions (eg, visual and hearing impairments, mental health problems) and higher rates of morbidity and mortality than the general population.⁵

Aging with IDD can be complex, as the aging process varies depending on the underlying condition—adults with Down syndrome, for example, experience accelerated aging including a genetically elevated risk of developing Alzheimer disease. The diagnosis and management of Alzheimer disease in persons with Down syndrome is further complicated by increased risk of hypothyroidism and depression. This can make it much more challenging for FPs to care for persons with IDD as they age.

In an important commentary in this issue (page S5), Sullivan et al make the case that, in spite of the challenges,

FPs are ideally positioned and skilled to improve the health of older adults with IDD.⁷

There are 3 key ways FPs can help improve care for patients with IDD. The first is by adopting a developmental approach to care. In particular, Sullivan and colleagues argue that regular periodic health assessments using reminder tools specifically designed to address the needs of persons with IDD, such as the Health Check tool, are invaluable.⁷ Research (page S59)⁸ in the special issue supports this, and a Praxis article illustrates how to effectively use this tool (page S33).⁹

A second aspect of caring for persons with IDD where FPs can have an effect is supporting greater autonomy and shared decision making.⁷ Another Praxis article in this issue shows how (page S27).¹⁰

Last, Sullivan et al discuss that one of the key ways in which FPs can have an effect is by recognizing and addressing the vulnerability of aging persons with IDD.⁷ While FPs can help promote the autonomy of older persons with IDD, they can also play an important role in protecting them from harms, especially in situations where patients' autonomy or decision-making capacity might be undermined. This is particularly important in decisions about end-of-life care. Resources such as the Decision Making of Adults with Intellectual and Developmental Disabilities: Promoting Capabilities, available from Surrey Place online,¹¹ can support FPs in this role.

Family physicians will find this special issue of the journal and the links to the many resources referenced invaluable in caring for persons in their practices with IDD. 🌿

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