Aging that includes an intellectual and developmental disability

A time to flourish?

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An article in this special issue (**page S30**) discusses the story of Sarah, a 52-year-old woman with Williams syndrome, who enjoys singing with friends in a choir and participating in a day program.[1] Gradually she has been resisting being involved in these activities. Lately, she has had falls outside the home and increased difficulty hearing. Sarah's day program can no longer accommodate her because she has started behaving aggressively toward others. Sarah's sister, who is her primary caregiver, is distressed. So is Sarah. This perplexing scenario is common enough. Could the changes in Sarah's life be signs that she is aging, despite her relatively young chronologic age?

People with intellectual and developmental disabilities (IDD) are living longer than ever before. This is a testament to many factors, including the efforts of dedicated, caring, and skilled family physicians and caregivers. But there is more that could be done to enhance the well-being of people with IDD as they grow older. Their average life span of 66 years remains considerably shorter than that of members of the general population.[2] They become frail earlier and sometimes at faster rates; yet health care and social service providers tend not to recognize that these patients are aging because of their young chronologic age.[3,4] They have fewer supports to prepare them for retirement and the end of life. Preventive care to address developmental needs and health risks associated with these late-life phases is often not provided for older adults with IDD. When a decline in health or abilities occurs, services and supports typically do not adjust to meet their specific increasing needs.[5]

The ethicist Daniel P. Sulmasy coined the term *inflorescent dignity* to describe the flourishing life that health care professionals and systems can promote in patients even as their health and abilities decline.[6] Aging and retirement should be times when everyone's life continues to flourish. This special issue of *Canadian Family Physician* focuses on improving the health and well-being of adults with IDD who are undergoing transitions to late-life phases or who are already in those life phases. Because most such patients do not meet inclusion criteria for geriatric health services or social services for aging persons, family physicians have a crucial role in caring for them well. Family physicians are best situated to optimize the health of older adults with IDD. They can provide preventive care and advance care planning; advocate for resources to support patients' well-being and flourishing; avoid interventions that these patients do not want; and prevent inappropriate visits to the emergency department, prolonged stays in hospital, premature placement in long-term care facilities, and harmful extreme polypharmacy.[7] They can also alleviate the stress of the caregivers of these patients who themselves are aging. This contributes to the well-being of both caregivers and patients.[8]

Adopt a developmental approach to care

As Sarah's situation illustrates, achieved developmental skills and functioning of adults with IDD can change over time. For people with IDD, these changes occur at different times during adulthood. Early screening for certain age-associated conditions or aging effects of specific genetic syndromes, such as Alzheimer disease in adults with Down syndrome (**page S25**)[9] or hearing loss in adults with Williams syndrome, is vital for caring well for adults with IDD. The "Primary care of adults with intellectual and developmental disabilities. 2018 Canadian consensus guidelines"[10] recommend performing periodic comprehensive health assessments using tools adapted to the specific health needs of these patients, such as the comprehensive health assessment (Health Check) (**page S33**).[11,12] Articles in this special issue affirm the value of periodic Health Checks in improving quality of care for adults with IDD (**page S59**).[13] They also identify barriers and facilitators to family physicians offering such Health Checks and patients being able to access them (**pages S47** and **S53**).[14,15] The research published in this supplement suggests ways in which improvements can be made. As with any tool, use of the Health Check should be guided by the family physician's judgment, taking into account the patient's context and perspectives. Certain assessment procedures might need to be adjusted, or alternatives offered, to accommodate patients' distress or to pursue goals of care agreed on by the patient, with the support of caregivers if needed.

Aging is associated with declining functioning and growing dependency on others. For older adults with IDD, this includes stress in trying to keep up with what others expect of them, experiencing losses, insecurity, and increased isolation and loneliness. These can have compounding negative effects on the health and well-being of older adults with IDD.[16] As their needs increase, the level of their supports should also increase.

Anticipating and recognizing changes associated with aging will enable family physicians to arrange or advocate early for increased supports. These include physical and occupational therapy, behavioural interventions, psychogeriatric counseling, social supports, and respite for caregivers. Sue et al (**page S19**)[17] discuss another important support that is often not available to older adults with IDD but that should be—namely, palliative care adapted to the needs of adults with IDD.

A developmental approach to caring for older adults with IDD must be holistic. Aging and the end of life are times when exploring meaning and generating something worthwhile that endures from one's life become especially important developmental tasks.[18] Many older adults with IDD can be supported to engage in these tasks. This can include psychosocial and spiritual care, such as creating a life story, participating in a support group or a faith community, meditating, praying, or engaging in some form of spiritual or other activity that the patient enjoys. Such activities can soften suffering, bring peace, enhance resilience, and ease adjustment to various aging-related changes in functioning and living.

Support decision making and increase autonomy

One area that is often overlooked when considering supports for older adults with IDD is decision making. The United Nations' Convention on the Rights of Persons with Disabilities, which Canada has ratified, declares that such persons have the right on an equal basis with others to make their own decisions, with support as needed, and the right to informed consent for health care, with reasonable accommodations for that purpose.[19] As they age, adults with IDD who are capable of independent decision making might sometimes need additional assistance from care providers or persons close to them who can reliably interpret their goals and preferences and help them weigh options for medical interventions. Another case presented in this issue (**page S27**) illustrates how participating in supported decision making better reflected the goals and preferences of a man with IDD than having a substitute decision maker take over his health care decision making entirely. His supporters were able to assist him in expressing his goals and preferences and in assessing benefits, risks, and burdens of various options for end-of-life care.[20] The legal structures that allow for supported decision making, however, are not in place everywhere in Canada. Family physicians can play a key role in the lives of older adults with IDD as advocates for legal reform in this area. In addition, while working within existing structures in their location, they can promote the involvement of adult patients with IDD as much as possible in making decisions that affect their health care. Tools, such as Decision Making of Adults with Intellectual and Developmental Disabilities: Promoting Capabilities, can provide guidance to family physicians (**page S27**).[20,21]

Advance care planning for the whole continuum of aging is another crucial role of family physicians in supporting older patients with IDD and their caregivers.[22] Such planning includes discussing periodically, with these patients and their caregivers, their goals, preferences, and plans for patients' retirement and other stages of aging, as well as anticipating end-of-life care.

Recognize and address vulnerability

While promoting the autonomy of older patients with IDD, family physicians also have a role in preventing harms to these patients. Tools, such as Decision Making of Adults with Intellectual and Developmental Disabilities: Promoting Safety (**page S27**),[20] can assist family physicians in reviewing factors in patients' contexts that might undermine patients' active role or capabilities for decision making.[23] This includes inappropriate taking over of decision making by others or inducement to consent to, refuse, or request interventions that these patients with IDD do not intend and would otherwise not accept.

To be avoided, on the one hand, is neglecting to offer medically indicated interventions on the basis of discrimination against age or disability or both. Equally to be avoided are interventions that do not reflect what older patients with IDD intend or would prefer based on their goals and hopes for a good life. For example, certain intensive end-of-life interventions that older adults with IDD who are dying might not have been involved in choosing can have burdens for them that are disproportionate to the life they hope for as they die.

Of concern also are certain interventions that adults with IDD might be induced to request. These are interventions that affect fundamentally and permanently the patient's physical or mental integrity, or deprive them of their life. For instance, Canada's law and regulations on medical assistance in dying do not provide sufficient guidance to physicians and nurse practitioners on screening for vulnerability in decision making due to the person with IDD's lived experiences, social conditions, or other factors. Nor do they take into account the complexity of assessing suffering in persons who have experienced lifelong disabilities. Older adults with IDD can be substantially affected by others who manifest or communicate negative views regarding the quality of a life that includes IDD or the burden on others of caregiving. This is especially true when adults with IDD are declining in functioning and growing in dependency on others. A research article on 9 euthanasia cases in the Netherlands between 2012 and 2016 that involved adults with intellectual disability or autism spectrum disorder found that most of these adults requesting euthanasia described their suffering in terms of an inability to cope with changing circumstances or increasing dependency. For a few, the basis of the request was the disability itself

and not any acquired medical condition.[24] While Canada's law on medical assistance in dying does restrict eligibility for this procedure to those whose natural death has become reasonably foreseeable, this condition is open to varying interpretations and has been challenged in the courts. Canadians should ensure that alternatives to medical assistance in dying, such as good palliative and end-of-life care,[25] are provided for older adults with IDD who hope for a flourishing life as they adjust to declining functioning and increasing dependency.

Maintain solidarity

As older adults with IDD age, family physicians should maintain solidarity with them and their caregivers. They can do this by accompanying and guiding patients and their caregivers who are adjusting to changes associated with late-life phases and facing new challenges. By adopting a developmental approach to care, and with judicious use of Health Checks, family physicians can provide preventive care and advocate earlier for holistic supports. They should involve older adults with IDD as much as possible in advance care planning and health care decision making, while taking steps to screen for and address vulnerability. With increased understanding of changing developmental needs associated with increasing frailty, family physicians have an important role and new opportunities to contribute to promoting and nurturing health and well-being in older adults with IDD. Aging that includes IDD can be a time to flourish. Providing such care can also be family medicine's time to flourish.

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