

Supporting adults with intellectual and developmental disabilities to cope and thrive through transitions to later-life phases

William F. Sullivan MD CCFP(COE) FCFP PhD John Heng MA
Dara Abells MD CCFP MScCH Andrea Perry MSc(OT) MHSc Megan Henze OTReg(Ont)

Guideline 12 of the “Primary care of adults with intellectual and developmental disabilities. 2018 Canadian consensus guidelines”¹ recommends preparing early for persons undergoing life-phase changes and other transitions. This entails attending to the health, psychosocial, and spiritual or existential needs associated with the person’s developmental life phase, declining functioning, and context. It also entails developing a transition plan to meet the increasing needs of persons with intellectual and developmental disabilities (IDD) and their support system in a realistic and sustainable manner by continuing and offering increased health care, social, and other supports. Guideline 12 needs to be understood in the context of all 32 guidelines and the related tools, some of which this case highlights. The journeys of adults with IDD transitioning to later-life phases and those of family caregivers who accompany them can be complex. Family physicians, especially those working in a Patient’s Medical Home model, can play important roles in facilitating this journey through assessment and planning.

Older adults with IDD do not transition to later-life phases at any predetermined age. This contrasts with youth with IDD whose transition to adulthood is marked by them reaching specific ages stipulated by their health and social support systems.² In countries where people with IDD can access good health care, they live to about 66 years of age on average.³ Compared with people in the general population, this represents a decreased life expectancy of about 20 years. For people with IDD in the severe to profound ranges of impairment who are medically complex and have multiple comorbid health conditions, their life expectancy can be about half that of others with IDD.⁴

There are also differences in the aging process and causes of death among people with IDD as compared with those in the general population. For instance, middle-aged adults with IDD are at greater risk of vision and hearing impairments, thyroid disorders, respiratory diseases, nonischemic cardiac disorders, obesity, osteoporosis, and mental health disorders.⁵ They manifest higher rates of frailty and greater severity of frailty scores 30 years earlier than adults in the general population. Hence, 50-year-old adults with IDD tend to have frailty scores comparable to 80-year-old adults in the general population.^{6,7} Adults whose IDD is due to a known genetic cause can also experience unique aging patterns. For example, people with Down syndrome are at

increased risk of developing dementia at an earlier age (50 to 55 years old) and adults with Williams syndrome have high rates of premature hearing impairments.⁸

In addition to these health needs, as with those in the general population, adults with IDD encounter psychosocial and spiritual or existential challenges and tasks when they enter later-life phases. For people with IDD, these involve developing and maintaining habits, skills, and attitudes needed to adapt to various losses. Such losses include those resulting from increased frailty related to aging, illnesses, injuries, worsening of or new disabilities, and greater social interdependency. In preparing for a foreseeable death, adults with IDD face, as do those in the general population, the challenge of discovering how they can be sources of generativity to others. Family caregivers often must face their current and future limitations as caregivers and proactively seek and accept help from others within and beyond their family. This includes developing habits, skills, and attitudes needed to acknowledge and value the generativity and reciprocity of their family’s legacy of care of their aging member with IDD.

Case

Sarah is a 52-year-old single woman with IDD. When she was 16 years old, she was assessed to be in the moderate range of severity (ie, a mental-age equivalence of 6 to 9 years old). Her IDD is caused by Williams syndrome. She also has several health comorbidities including visual impairment (she wears glasses), constipation, obesity (body mass index of 35 kg/m²), and type 2 diabetes (which is managed with glyburide). She lives with her older sister Gloria and her sister’s husband, both of whom work and are Sarah’s main caregivers. Sarah attends a day program 3 days each week and she sings in the choir of a Christian church, which she attends twice weekly. She has enjoyed both activities since she was a young adult. You have been Sarah’s family physician for 10 years and work in a community-based family health team (FHT). Sarah usually comes to appointments with Gloria. You generally see Sarah annually for a Health Check, every 3 months to manage her diabetes and other health issues, and as needed based on Sarah’s or Gloria’s concerns.

Gloria brings Sarah to your office 6 weeks following her last appointment owing to concerns regarding changes in her level of functioning. Gloria reports that, since their last visit, Sarah is having

increased difficulty hearing. She has also had 3 falls in the past 3 weeks when walking outdoors, which no one witnessed. These have resulted in some low back pain but no other identified injuries. Since these falls, Sarah seems sleepier and is avoiding her usual involvement in activities at her day program. She has also stopped going to church. She has been engaging in new aggressive behaviour toward others (verbal and physical) associated with her avoidance of usual tasks and activities. Gloria has also noticed that Sarah appears unable to complete some familiar activities of daily living, such as dressing and putting away her clothes. The manager of the day program warned Gloria yesterday that if Sarah's new aggressive behaviour continues, she would be unable to continue coming to the day program. Both Sarah and Gloria appear fatigued and distracted during the assessment. Gloria asks you what she should be doing to help Sarah.

Discussion

This case raises the issue of adults with IDD transitioning to later-life phases. Such life transitions are periods of change that are the most challenging for people with IDD and their caregivers. This is a time when family physicians can play an important role in accompanying their patients with IDD and family caregivers, identifying and normalizing some of the challenges being faced, and providing anticipatory guidance, care plans, and needed supports to enable them to cope and thrive through this transition. This case also illustrates the family physician's perspective when encountering high levels of uncertainty and ambiguity that characterize the presentation of a middle-aged adult with IDD who is on the threshold of transitioning to a later-life phase. Despite being only 52 years old, Sarah presents with symptoms and signs of aging that relate to the cause of her IDD (Williams syndrome) and her medical comorbidities. Her current social and other supports do not enable her to cope with new adversities related to frailty and the cascading effects precipitated by falls that have destabilized her previous equilibrium. The level of complexity that family physicians encounter in such presentations is comparable to what they might encounter among their 80-year-old patients without IDD, although the latter are likely able to describe more details regarding their experiences.

It is helpful for the family physician and FHT in this case to explore Sarah's perspectives on what has been happening, and what her life goals and goals of medical care are. The medical focus of the case is on changes to Sarah's health, some of which are related to increasing frailty and other circumstances. On a human level, it is important to ask how Sarah is adapting and coping with such changes even when the medical reasons for them remain to be understood. Have they affected her capacity to communicate? Has she experienced some trauma, either physical or psychological? What are her strengths and skills that could inform a solution-focused approach

to address her experiences of a changing life? Could what she is experiencing be part of the aging process typical in much older members of the general population? If so, might others be expecting more than is realistic for someone with her level of disability and frailty?

Based on a better understanding of Sarah's experiences, it turned out that a choir member she was close to had recently died. Sarah was both mourning this loss and grappling with her own mortality as she ages. This had become more of a concern as she noticed herself slowing down, losing her hearing gradually, and sometimes losing balance. Sarah's concerns included spiritual and existential ones. A pastoral care worker provided an adapted spiritual needs assessment that highlighted important issues. The social worker facilitated connecting Sarah to her church's programs, which were able to accommodate her desire to learn about mindfulness meditation and other practices.

What about Gloria? Family caregivers of aging adults with IDD often experience considerable mental, physical, or economic stress in balancing the person with IDD's increased support needs with other responsibilities.⁹ It is important for Sarah's family physician to ask Gloria about her stressors and worries as a caregiver. What are her perspectives regarding goals of care for Sarah and hopes regarding possible interventions? Where are she, her husband, and her other siblings in their own family life phase, and is this in tension with where Sarah is in hers? It turned out that one thing that was troubling Gloria was Sarah's increasingly messy eating habits. Following some teaching regarding Sarah's decline in fine-motor skills associated with frailty, her family physician recommended taking a compensatory approach and involving an occupational therapist to adapt eating utensils to accommodate Sarah's diminished fine-motor skills. On further discussion, it turned out that Sarah's table manners did not bother Gloria but rather her husband. This issue had precipitated a conflict in their relationship, which related to her husband's perception of ever increasing burdens of caregiving on their family. Although Gloria and her husband were not patients of Sarah's family physician, they did agree to complete a Caregiver Stress Scale, which showed a considerable amount of stress for each. On the basis of this finding, Sarah's family physician made recommendations to his colleague regarding supports and counseling for the family, including referrals to the FHT's social worker, a respite care program, and a personal support worker for Sarah.

What is the role of Sarah's family physician in this case?

One role is to take a systematic diagnostic approach by identifying and relating various causes that might be affecting Sarah's health decline and new behaviour.¹⁰ It is important to consider such causes sequentially. A diagnostic approach based on the acronym HELP (ie, physical Health, enabling Environments, Life experiences,

and Psychiatric conditions)¹¹ can be useful. In Sarah's case, review of her medications revealed that medication-related hypoglycemic episodes might have been the cause of her falls. A painful fall-related back injury was causing impaired sleep and irritability, and increasing frailty manifested in deconditioning and a decline in gross- and fine-motor skills. These put her at risk of more falls. Losses in her friendship at church and in her functioning were contributing factors to compromised psychosocial and mental well-being. These led to new behaviours that challenge. Functional decline should not be prematurely attributed to dementia or a psychiatric condition without adequate assessment of physical health, environmental factors, and life experiences.

A second role of the family physician is to support or lead the development of a care plan. This assumes that the family physician or another member of the FHT will oversee implementing this plan with various disciplines working together as an integrated team in a Patient's Medical Home model. Such a plan should distinguish the roles and responsibilities of various involved stakeholders, including patients and caregivers, the family physician and FHT members, medical and developmental specialists, and system navigators. Each of these stakeholders should have a designated lead and assigned tasks and timelines.

A third role of the family physician is to instigate and possibly facilitate developing a transition plan by working collaboratively with the FHT's system navigator. Such planning requires being familiar with provincial social services systems, which are typically outside the usual health services systems. This might involve helping Sarah to be reassessed based on her increasing needs and those of her family (eg, for personal support workers, respite, and residential and legal services).

The 2018 IDD guidelines,¹ the Health Watch Table for Williams syndrome,¹² and a range of other tools developed by the Developmental Disabilities Primary Care Program¹³ are helpful resources that can be used to support patients like Sarah in this case.

Conclusion

Increasing frailty in adults with IDD is a good indicator to begin to prepare for the transition to later-life phases, even if this is at a relatively young age (eg, early 50s, as with Sarah, or 20 years of age in people with IDD in the severe to profound range and multiple medical comorbidities).

Adults with IDD and their families find transitions to later-life phases to be among the most stressful times of life. An important role of a family physician is to accompany them during this stressful time. In addition to assessing and addressing medical concerns, family physicians are ideally situated to provide basic teaching, coaching, and planning with their patients with IDD and caregivers.

This new and challenging role entails

- functioning in a Patient's Medical Home model, which provides continuous care and integrates a range of relevant inputs;

- systematically determining the causes of health and other issues relevant to the transition;
- drawing on the knowledge and skills of members of an interdisciplinary FHT to assist with proactive assessments and care and transition plans; and
- overseeing implementing these care and transition plans.

Transition plans should address ongoing, increasing, and new needs of adults with IDD (including psychosocial and spiritual or existential ones). This should be done by advocating for enhancing or adjusting the patient's support systems to meet these changing needs. This is a role that some FHTs can delegate to a system navigator.

While implementing transition plans, family physicians should continue to focus on supporting the health and well-being of their patients with IDD to help them cope and thrive through their transitions. This should also include checking in on the health and well-being of family caregivers and, if needed, facilitating or advocating for their 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 and the Academic Family Health Team at St Michael's Hospital, and Clinical Lead of the Developmental Disabilities Primary Care Program, Surrey Place.

Professor Heng teaches in the Department of Philosophy and the Department of Interdisciplinary Programs at King's University College at the University of Western Ontario in London. **Dr Abells** is a family physician at Forest Hill Family Health Centre in Toronto and the Integrated Services for Autism and Neurodevelopmental Disorders, and Lecturer in the Department of Family and Community Medicine at the University of Toronto. **Ms Perry** is Transitions Facilitator for the Developmental Disabilities Primary Care Program, Surrey Place. **Ms Henze** is Transitions Facilitator for the Developmental Disabilities Primary Care Program, Surrey Place.

Competing interests

None declared

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