Aging and Developmental Disabilities: Challenges and Opportunities

By Sandy Stemp and Cindy Stephens

Individuals with developmental disabilities (the outdated term "mental retardation" is not used) are living longer, with some experiencing a normal lifespan. Even those with specific syndromes or neurological conditions such as Down's syndrome are reaching older ages, although their lifespan is still generally shorter than that of the general population. Agencies are using ages 50 or 55 years when reviewing demographics and proactively planning for seniors with a developmental disability.

In Canada, individuals with developmental disabilities belong in mainstream society and many persons with developmental disabilities now live within the community. An important move to integration in Ontario was the closure of all institutions specifically designed for individuals with a developmental disability that segregated them from others. Advocacy efforts across the country have worked toward ensuring equal rights and access to services for these individuals. This has included inclusive education efforts and employment opportunities, as well as ensuring all people can participate fully in the community.

As individuals age, there is a new challenge for inclusion: access to the full range of senior programs, services and supports. Senior services generally lack knowledge and experience, having never or rarely come into contact with individuals with developmental disabilities. Conversely, the developmental disability service sector lacks knowledge on aging and senior services. While this can be problematic, it also presents opportunities for both sectors to work together in collaborative partnerships to successfully support those aging with a developmental disability.

When individuals have required lifelong support, the question arises as to when the support of senior services will be required—specifically, a long term care (LTC) home. The answer is the same as for any adult: when the current supports (family or agency) are no longer able to provide the assis-

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Need to know: Working together

Education and awareness:

- Seek information (e.g., from the Aging and Developmental Disabilities Community of Practice).

Network and partner:

- Connect with the local developmental services system (or OPADD regional committee).
- Conduct visits, cross-training and meetings to build understanding and knowledge.

Planning and transition:

- Develop a transition and support plan with the individual and his or her family and care team from both the LTC home and developmental services agency.
- If an agency is not involved, connect with your developmental services partners for support and resources.
- Plan a potential enhanced staffing model and other supports (e.g., behaviour management).

Maintaining the relationship:

- Discuss, define and change roles and responsibilities as needed.
- Nurture relationships at the personal support worker, manager and administrator levels through both partner organizations.
- Engage in ongoing communication and problem-solving at all levels.
- Be open to different plans and strategies that are jointly developed—consider what works best for the individual.

tance the person requires to live safely in the community. Staff in developmental disability agencies usually have a background in social services. Most do not, however, have health care training or experience. They are able to support the person's developmental disability, but may struggle to provide appropriate support for age-related changes. Education on aging is necessary for these workers to understand and better support people as they grow older. Once health issues become complex and safety issues put the individual at risk, additional services should be accessed.

Collaboration

Developmental disability agencies are encouraged to access home care services and other community senior services (such as adult day programs) before considering referral to an LTC placement. Yet many of these agencies are not aware of senior services that can be accessed, or have difficulty accessing those services. This may be due to senior services feeling they are not well equipped to support an individual with a developmental disability. Some senior agencies wonder why separate aging services are not developed for such people. However, duplicating senior services would be impractical, inefficient and not in keeping with the principles of integration.

As the aging trend continues, many developmental disability agencies and families of adults with developmental disabilities are feeling the pressure to plan. One response to this pressure was the creation of the Ontario Partnership on Aging and Developmental Disabilities (OPADD) in 2000, following a symposium on aging hosted by the Reena Foundation and funded by Health Canada's Population Health Fund. OPADD was formed on the premise that providing the best quality of support for aging individuals with a developmental disability lies in collaboration between systems of care.

One of the tasks of OPADD was to develop eight regional cross-sector committees to plan conferences, bringing together

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Need to know: Individuals

- An individual with a developmental disability is unique; each person will have his or her own strengths and needs.
- Individuals may communicate atypically, but are usually understood by their caregivers. Ask and learn from family and staff from their agency.
- Challenging behaviour is often related to difficulty in communicating needs.
- Routine and certain activities may hold tremendous meaning and importance for individuals. Ensure these are known and communicated to all staff.
- A consistent approach is very important.
- Behaviour therapists from the developmental disability sector can be helpful as part of the team.
- When staff from both sectors work together as a team and share information, the individual benefits greatly.

the two sectors to look at how they can develop partnerships and collaborative models. Follow-up conferences were also held and collaborative projects specific to each region initiated. In 2008, OPADD became a Community of Practice (CoP) through the Seniors Health Research Transfer Network. The CoP was a great way to sustain the OPADD network by virtually connecting all interested parties through technology and webinars. Both OPADD and the CoP have highlighted successful cross-sector collaborative models and engaged others to develop partnerships in their communities.

Success stories

An example of a successful collaboration is the partnership between the Cummer Lodge and Reena. Cummer Lodge is a 391-bed municipal LTC home in Toronto. The director of nursing at Cummer Lodge participated in an OPADD event and was open to new partnerships. Reena and Cummer Lodge began discussions about the admission of an individual with Down's syndrome experiencing dementia. Reena staff toured Cummer Lodge and Cummer staff toured the individual's group home. A transition plan was developed. This included intensive staffing support for the first few days and tapering off in the following weeks, followed by ongoing staffing support. Education (information about the individual) was shared by the Cummer Lodge staff when the person moved in, and continued when Reena staff interacted with those from Cummer Lodge. The Reena staff support continued for four hours a week. Reena was involved in all areas, including meetings at the home and assistance with family support and consent.

This model has evolved over the past eight years, and eight adults with developmental disabilities now live in various units at Cummer Lodge, with three full-time Reena staff providing support. Reena and Cummer Lodge have built an effective relationship and partnership. Both organizations support each other, with understanding and communication key to resolving issues or problems. Reena also provides behaviour therapy support and maintains each person's connection to his or her home community and friends. It provides social/recreational support for Cummer Lodge activities or additional pursuits that help to support an individual, such as taking a person with significant physical disabilities to a therapeutic pool. Reena has also developed partnerships with the Baycrest Centre for Geriatric Care, where it supports individuals in their LTC home (the Apotex Centre) and adult day programs.

Other models of collaborative partnerships can be seen in Ontario. Coleman Care Centre in Barrie (part of Schlegel Villages) has a long history of expertise in supporting individuals with developmental disabilities in an LTC home. They fully integrate workers from Simcoe Community Services as part of their support team. The director of care says significant learning has occurred through this cross-sector partnership. She has found that strategies, programs and even equipment in developmental disability services can be successfully transferred and applied to all seniors.

Mary Centre, a developmental services agency in Toronto and Peel Region, was founded for seniors with a developmental disability. It has broad connections with senior services, runs an integrated adult day program and has strong relationships with many LTC homes. The Alice Saddy Association in London also has a unique outreach program.

These agencies have connected with developmental services organizations in their communities and offer support for both transition and ongoing living within LTC homes. They assist homes in understanding their finances (individuals younger than 65 years often receive funds from the Ontario Disability Support Program) and consent and capacity issues. They also offer additional supports, such as behaviour therapy and connections to previous workers, whose understanding of what works best for the individual can help with any issues that arise. It is important to realize that the partnerships are not only about admission to an LTC home, but may also involve moving from an LTC home back into a community setting. Individuals with a developmental disability who enter an LTC home because of a crisis or breakdown of family support may be better placed in a community setting. The partners will then work together to refer the individual to the developmental disability service sector for a community residence.

Planning for an older generation

The prevalence rate for developmental disability in the general population is about one to three per cent, and less for the older population. Although the prevalence is small, the consequences of inadequate planning are significant. Individuals with a developmental disability are living longer than ever before. This is a major success and should be celebrated. With this success, however, comes the challenge of inclusion in all areas of senior support.

Individuals with a developmental disability will have unique needs that staff in LTC may not understand. This can lead to

serious problems, crisis and failed placements. It may also lead to exclusion, with individuals not being accepted into services because of past problems. These challenges can be met through collaborative partnerships, which may lead the way for innovative support models for seniors.

Collaboration, working together and sharing resources are the keys to these new challenges and opportunities. Through new partnerships, the senior and developmental disability sectors have demonstrated success in supporting individuals aging with developmental disabilities. LTC

Further reading

Through the Seniors Health Research Transfer Network (SHRTN), the Aging and Developmental Disabilities Community of Practice is connected to an information specialist. For more information on articles (and full text on the below articles) on aging and developmental disabilities, contact Lindsay Ogilvie at the SHRTN Library Service Guelph (logilvie@sjhcg.ca).

- Kim NH, Hovek GE, Chau D. Long-term care of the aging population with intellectual and developmental disabilities. *Clin Geriatr Med* 2011;27(2):291–300.
- Patti P, Amble K, Flory M. Placement, relocation and end of life issues in aging adults with and without Down's syndrome: A retrospective study. *J Intellect Disabil Res* 2010;54(6):538–546.
- Perkins EA, Moran JA. Aging adults with intellectual disabilities. *JAMA* 2010;304(1):91–92.
- Torr J, Strydom A, Patti P, Jokinen N. Aging in Down syndrome: Morbidity and mortality. *J Policy Pract Intellect Disabil* 2010;7(1):70–81.
- Jenkins EC, Ye L, Gu H, et al. Shorter telomeres may indicate dementia status in order individuals with Down syndrome. *Neurobiol Aging* 2010;31(5):765–771.
- Strydom A, Shooshtari S, Lee L, et al. Dementia in older adults with intellectual disabilities—epidemiology, presentation and diagnosis. *J Pol Prac Intellect Disabil* 2010;7(2):96–110.

For more information

The Reena Foundation is a developmental disability service organization in Toronto and the York region that supports 308 individuals within a range of residential settings. Currently, more than half the residents are older than 50 years—a demographic trend similar to that of many other developmental disability service organizations.

The Aging and Developmental Disabilities Community of Practice (CoP) is working with Dr. Nancy Jokinen, assistant professor at the School of Social Work, University of Northern British Colombia (jokinenn@unbc.ca), who is the lead for a national survey on the learning and information needs of caregivers to support individuals with a developmental disability and dementia. Join the CoP for more information this project.

To find out more about OPADD, SHRTN and the example collaborative models described in this article, contact Sandy Stemp at **sstemp@reena.org** or **905-889-2690 ext. 2227**.