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sur le troisième âge

Aging with a developmental disability



Seniors on the margins

Canada

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SENIORS ON THE MARGINS... is a series of policy papers presenting NACA opinions and recommendations on the needs and concerns of seniors who are marginalized, or at risk of marginalisation in Canadian society.

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Table of Contents

Preface	1
Introduction	2
Definitions	2
Overview	3
Key issues	4
Physical health	4
Mental health	5
<i>Recommendations</i>	7
Family and social support	8
<i>Recommendations</i>	10
Work, retirement and economic security	11
<i>Recommendations</i>	12
Housing and services	12
<i>Recommendations</i>	14
Conclusion	15
Acknowledgements	16
References	17

Aging with a developmental disability

Preface

By 2021, seniors will form 18% of Canada's population, compared to 12.5% in 2000. This aging of Canada's population supposes a need for responsive policies, programs and services to serve the growing number of Canadian seniors. While general consciousness of this need is rising and some changes are very slowly taking shape to address them, we need to ask if the effort to adapt our society takes into account the seniors of Canada who are not part of the mainstream... those from ethnic minorities, those who have lived with developmental disabilities, those with low incomes, etc.

According to a UNESCO definition, "marginalization occurs when people are systematically excluded from meaningful participation in economic, social, political, cultural and other forms of human activity in their communities and thus are denied the opportunity to fulfill themselves as human beings." In this land of equal opportunity, how are Canadian seniors on the margins faring?

The NACA publication series **Seniors on the margins** looks at the situation of those Canadian seniors who, because they are not part of the majority, may not have access to the resources needed to age in comfort and health. In each paper of this series, NACA examines the causes and key issues of marginalization and proposes strategies and recommendations. The present paper looks into the situation of Canadian seniors aging with a *developmental disability*.

The National Advisory Council on Aging (NACA) is an arm's length body of citizens appointed by Order in Council to counsel the Minister of Health on issues pertaining to seniors' health and the aging of Canada's population.

Introduction

As a result of progress achieved in medical science and health care, Canadians with developmental disabilities now have a life expectancy that extends beyond mid-life. Improvements in their health and life expectancy have coincided with a dramatic shift in public and professional attitudes toward them and in approaches to service delivery. Once regarded as patients who were entirely dependent upon custodial care provided in large institutional settings and who had few, if any choices or rights, persons with developmental disabilities are now considered full citizens entitled to receive a range of services of their choosing to maintain their quality of life and enjoy full inclusion in society. Despite these positive trends, older adults with a developmental disability are still an under-served and marginalized group.

This document describes NACA's position on the situation of Canadians who are aging with a developmental disability. It identifies a number of gaps and challenges with respect to the unmet health care, social and financial problems that impact on their capacity to age well and provides recommendations for action in each of these areas.

Definitions

A developmental disability is associated with many conditions that originate prior to birth, at birth or in early adulthood but the primary disability is intellectual. The conditions present varying degrees of intellectual deficiency, along with other physical and/or sensory incapacities and health risks. Persons with a developmental disability form a varied group that can be classified into three broad categories:

- *genetic syndromes* such as Down Syndrome, Fragile X Syndrome and Prader-Willi Syndrome;
- *problems with the central nervous system* which result

- in epilepsy, cerebral palsy and visual impairments; or
- *milder developmental disabilities*.¹

Because there is often a tendency to focus on the primary intellectual disability, other accompanying physical and/or sensory disabilities are often not taken into account in planning and delivering services for them. The level of disability is still largely measured by an IQ scale based on the normal population.

Overview

The rate of developmental disability among Canadians aged 15 years and over in 2001 was 0.5 percent or 120,140 persons.² Of these, an estimated 44,770 persons are aged 45-64 and 11,080 are aged 65-74. These figures, however, represent an underestimation, in part because they exclude persons who are institutionalized or living in nursing homes as well as those residing in the territories and reserves.

Although there are no current Canadian data on the life expectancy of persons with a developmental disability, United States data show that many of those with milder disabilities are living as long as the general population.³ This means that many adults with developmental disabilities are now outliving their parents.

Ina who turned 65 last winter announced at her birthday party, "I'm not going to stop and get old." She works at *Community Living*, is an active volunteer and is a member of a local curling team.

Key issues

A number of factors contribute to the marginalization of seniors with developmental disabilities. The notion and the reality of "differences" in capacity have often caused them to live parallel lives socially and economically. This means that mainstream information on disease prevention may not be reaching them. This is compounded by the rarity of experts on aging with developmental disabilities and the difficulties of communication – possible factors in preventable or undiagnosed conditions, and lack of access to proper care and other services in the areas of physical or mental health. Social and financial supports are also critical to the continued well-being of seniors with disabilities.

Physical health

Specific sub-groups of persons with developmental disabilities have particular health risks or co-occurring conditions. For example, Down Syndrome is generally associated with the early onset of age-related visual and hearing disorders, epilepsy and dementia; Fragile X, with musculoskeletal disorders, visual impairments, early female menopause, and epilepsy; and Prader-Willi Syndrome, with obesity, a high risk of cardiovascular disorder and diabetes. Developmental disabilities associated with problems with the central nervous system are linked to higher rates of acute respiratory disease, epilepsy, autism, mental health problems and vision disorders.

Few health professionals have expertise in treating persons with developmental disabilities, and communication between the professionals and the patient can be difficult. For these reasons, many older persons with developmental disabilities develop chronic conditions or diseases that could have been prevented or treated earlier, if they had been detected.

Although the prevalence of sensory, visual or auditory impairment among aging persons with developmental disabilities is similar to those in the general population, the degree of impair-

ment may be more severe due to pre-existing problems. Also, compared to the general population, a greater number of people with disabilities have uncorrected or unidentified visual problems such as glaucoma, or inadequate prescription eyewear, in part because of their inability to communicate their needs clearly.

Older adults with a developmental disability may experience more severe loss of flexibility as age-related changes in joint function and bone density combine with their existing mobility problems. Also, they may be prone to developing arthritis at a younger age.

Health promotion and disease prevention can have a major impact on the functional ability, quality of life and longevity of seniors. However, people with developmental disabilities often lack basic education about the importance of healthy lifestyle choices and do not receive the same preventive health measures as other people (for example, pap smears and mammograms). Furthermore, transportation problems, cost barriers and a lack of suitable instructors make it more difficult for them to participate in health promoting physical and recreational activities.

Mental health

Behavioural and mental health problems are fairly common among persons with developmental disabilities. While it is estimated that 30% to 60% of persons with a moderate or severe developmental disability have a mental disorder, several factors

Janet, 56 years old, enjoys attending the regular Adult Day Program in her home town, twice a week. She participates in a variety of activities with the other older adults in the program. She is able to attend because the program is affordable and she feels welcomed by the staff and participants.

interfere with accurate diagnosis and treatment.⁴ Signs of mental health problems tend to be attributed to the individual's developmental disability, clouding detection of problems that are treatable. Differentiation between dementia, depression and those behaviours directly linked with the developmental disability is especially challenging, as is the difficulty the senior may have in expressing psychological problems. As well, there are few specialists with expertise in both developmental disability and psychogeriatrics.

Problems in diagnosing dementia, particularly among individuals with Down Syndrome arise for several reasons:

- the person's level of intellectual and functional impairment prior to the onset make it difficult to detect the early signs of dementia;
- language and communication impairments make it difficult for persons with developmental disabilities to relay information to health care professionals;
- atypical symptoms often surface and are overlooked until the dementia is quite advanced;
- sometimes people with depression and hypothyroidism can be misdiagnosed as having Alzheimer Disease because the symptoms are similar.

Recommendations for health and health care

- 1) Health professionals providing primary care to aging adults with developmental disabilities should:
 - educate and advise them on healthy lifestyle choices related to nutrition, oral hygiene, physical activity and tobacco avoidance
 - give family members and service providers directly involved in their care relevant information on their particular health needs and risks
 - regularly monitor their health as early as 40 years of age in order to detect and treat changes in sensory and cognitive functioning and chronic health problems as early as possible
 - monitor their use of prescribed and over-the-counter medications.
- 2) University, community college and continuing care curricula for health and social service providers and professionals should include education about developmental disabilities.
- 3) With federal and provincial government support, local health authorities should develop community-based health promotion programs that are accessible and adapted to aging persons with developmental disabilities.

Family and social support

Population aging and the de-institutionalization of persons with developmental disabilities have given rise to situations where parents in their eighties or nineties are still the primary caregivers of their developmentally disabled adult child in his/her fifties or sixties. Siblings as well (mostly sisters) often have an important role in providing emotional, functional and instrumental support. It is important to support families and to meet the eventual needs of aging caregiver parents. Also, families providing care to an adult with a developmental disability need better access to the information and services that can support them in this role.

When caregiving in the parental home is no longer possible, permanency planning or planning for supportive housing or eventual placement in a long-term care facility become necessary – for both the developmentally disabled adult child and the older parents.

Belonging in a community and being able to participate fully is key to maintaining quality of life.⁵ Older adults with developmental disabilities themselves identified the following factors as important for their social integration:

For over 15 years, Derek, 52 years old, was employed five days a week as a cleaner with a clothing manufacturer. When the factory suddenly closed, Derek felt lost and depressed. His skills were limited and he was unable to find other employment on his own. But things changed for the better when Derek was referred to the local Community Living Association. Although paid work could not be found, the association did find a part-time volunteer placement for Derek, cleaning the local church.

- settings which provide frequent and reliable opportunities for consistent social contact, e.g., work, day programs;
- structured recreation and leisure activities;
- friendships; and
- family.⁶

Day programs can provide ideal settings to promote and maintain social integration. Persons with developmental disabilities often have had few opportunities to make decisions for themselves. Their lack of experience in this area can create unnecessary dependency among those who do have the capacity for self-determination. Some older adults with developmental disabilities require the help of a substitute decision maker who may be a family member or a guardian appointed by court order. The selection of a substitute decision maker requires careful consideration to ensure the best interests of the older person with a developmental disability.

The Reena Foundation organized an Ontario-wide symposium in March 1999 to address the systemic barriers to accessing services by older persons with developmental disabilities and to facilitate collaboration between professionals working in the long-term care and developmental disability sectors. An important outcome was the creation of the Ontario Forum on Aging and Developmental Disabilities which allows both sectors to join forces in supporting and planning for this population. The Forum has since facilitated four workshops in various areas of the province to encourage communities to build local capacity and cross-sectoral co-operation.

Recommendations for family and social support

- 4) With provincial government support, local service agencies should provide a range of support services for aging adults with developmental disabilities that include outreach, information, assistance with activities of daily life (such as shopping and banking), adapted day programs and assistance in permanency planning well in advance of the need for placement.
- 5) Home care providers should provide respite care and homemaking services to family caregivers of older adults with developmental disabilities.
- 6) Municipalities should ensure that local public services, social, cultural and recreational facilities and public places are accessible and responsive to the needs of older adults with developmental disabilities to promote their independence, well-being and social integration.
- 7) All individual and community service providers and professionals should provide care and services to aging persons with developmental disabilities in a way that respects their decisional capacities, their values and their preferences in order to foster their empowerment.
- 8) Federal, provincial and municipal social and health programs and services targeted to seniors should relax age criteria for eligibility by older adults with developmental disabilities in recognition of their greater likelihood of premature aging.

Work, retirement and economic security

Work is not only a source of income but also a way to feel useful and to maintain social contact. In the past, persons with developmental disabilities typically were employed in sheltered workshops where work demands were adapted to their skills but which excluded them from the rest of society and paid lower wages. At present, working adults with developmental disabilities are more often employed in supported work environments involving mainstream types of employment with greater social inclusion and somewhat better pay. Many older workers with developmental disabilities prefer to continue working for as long as possible in the community mainly because work represents an important source of social support and integration.

As with the general population, older individuals with developmental disabilities are generally dependent on the public income system. Although they are entitled to receive Canada/Quebec Pension Plan payments (if they were employed) and Old Age Security, they will remain economically vulnerable as these payments will reflect their participation in the low wage sector. If they reside in a group home and have no income, the home's program funding provides for room, board and other support services; if they are employed or are receiving pension payments, they are expected to pay for these services.

As an alternative to group home funding, Saskatchewan, Alberta, Atlantic Canada and Ontario are currently initiating individualized funding whereby persons with developmental disabilities or their families are provided government funds directly for the purchase of disability-related goods and services. Although individualized funding is a positive development which respects individual choices and needs, its implementation is difficult because the required services may not be available and quality standards are not assured.

Further, provincial disability benefits appear to favour group homes relative to care at home. For example, in Ontario,

families providing care may receive between \$2,000 to \$3,000 per year whereas group homes operated by agencies receive \$55,000 a year per individual.

Recommendations for work, retirement and economic security

- 9) Federal and provincial governments should support a range of employment programs that promote and facilitate the integration of persons with developmental disabilities into sheltered or mainstream workplaces.
- 10) Federal, provincial and municipal social and health programs and services targeted to seniors should relax age criteria for eligibility by those older adults with developmental disabilities who have a greater likelihood of premature aging.
- 11) All governments providing, or intending to provide individualized funding for services should ensure that required services are available and are publicly accountable for service quality.

Housing and services

The living arrangements of Canadian seniors with developmental disabilities are not fully known. One recent national Canadian survey⁷ of developmental disability agencies in Canada suggests that most continue to have group homes as their dominant model of residential services, followed by independent apartment living (mainly in Ontario) and by other residential settings

such as foster families, home with parents, homes with house parents and boarding home services. However, this survey did not include persons living in institutions.

There is a movement toward smaller, home-like housing that allows adults with developmental disabilities to "*age in place*" rather than move to institutions. But few choices are actually available in Canada, waiting lists are long, and not all settings are adapted to specific needs. Caregiving parents find it extremely difficult to locate resources to help them plan for the time when they can no longer care for their son or daughter and consequently, adult children may be left homeless when their parents die.

Recognizing the lack of permanency planning as a potential risk for homelessness, service providers from the Community Living Renfrew County South (CLRCS) developed a project to minimize the risk of homelessness for older adults with developmental disabilities. They identified senior parents in the County caring for their older children with developmental disabilities and invited them to attend education sessions on permanency planning. Staff members were trained to inform and assist families in the preparation of short- and long-term plans for the care of their children. Local lawyers were also trained in developing wills and trust funds for families. Staff members are currently researching housing options that would allow senior parents and their adult children to remain connected with each other and to the community.

Many older persons with developmental disabilities live in rural or smaller urban areas⁸ where appropriate housing choices are in short supply. As well, although there are no specific data, it is likely that older adults with developmental disabilities are part of the 20% of seniors with disabilities who live in *core housing need* (i.e., either substandard housing or housing that is adequate but beyond their means).

Services for persons with developmental disabilities are delivered in a way that considers them as full citizens entitled to be treated with respect for their rights and fully included in society. Meeting their needs as they grow older becomes more complex because services for seniors (e.g., home care, institutional long-term care, public pension programs) are delivered as group programs and are not designed to adapt to individual needs and circumstances.

Co-operation between the "seniors" and the "development disability" sectors to provide support to a growing population of older persons with developmental disabilities is challenging because each sector has limited resources and is reluctant to take on another group of clients. Co-ordinating service delivery between sectors is difficult and service providers often lack the knowledge and experience with respect to either seniors or developmental disability. Despite these challenges, there is a willingness to collaborate.

Recommendations for housing and services

- 12) All governments should increase the number and variety of housing options for older adults with developmental disabilities and their caregiver parents, particularly in rural or smaller urban areas; options should include supporting housing with access to community services and facilities.
- 13) Service providers and professionals who provide support in permanency planning should include information and assistance that includes housing arrangements and estate planning.
- 14) Service providers working in seniors and in disability sectors should co-operate to respond in a flexible and co-ordinated manner to the needs of aging persons with developmental disabilities.

Conclusion

The increase in the numbers of people with developmental disabilities reaching their senior years is an indication of Canada's success as a society that supports all citizens. At the same time, it creates new challenges. Much remains to be accomplished to address the needs of older persons with developmental disabilities adequately and to promote their inclusion in Canadian society.

The Council hopes that the recommendations presented in this report will contribute to debate and action to ensure the well-being, respect, care and support of aging adults with developmental disabilities.

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1. There are some inconsistencies in labelling their disability, as service providers and advocates attempt to neutralize the stigma. For example, terms such as "mental retardation" or "mental handicap" are accepted in U.S. and France respectively but are rejected in English Canada where the terms "intellectual disability", "developmental disability" or "developmental delay" are preferred and considered to be less negative. Furthermore, Quebec commonly uses the term "déficience intellectuelle" (intellectual deficit) while the term "retard mental" (mental retardation) is falling into disuse.
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