Services for Seniors with a Developmental Disability

A Plain Language Summary

This review was prepared by the *Community Living Research Project* based at the School of Social Work and Family Studies, University of British Columbia. This document is part of a larger research project exploring the Community Living supports and services available locally, provincially, nationally, and internationally for adults with developmental disabilities.

Reading this report

This paper is a plain language report adapted from a full academic/government report called "Services for Seniors with a Developmental Disability: Literature and Initial Program Review" produced by the Community Living Research Project.

To help people read this report some words and phrases have been defined. Definitions are in brackets (example) and follow the word or phrase. Some words and phrases are underlined with a star at the end of the word (for example – definitions*). Words that are underlined can also be found in the "Glossary" at the end of the report.

To make reference to research, footnotes have been used in this report. Footnotes are noted in the report by a small number at the end of a sentence; the number can also be found at the bottom of the page followed by the researcher's name and the date of the research referenced. If you need more help reading this paper, please ask a friend.

For additional information and copies please contact:

Community Living Research Project
School of Social Work and Family Studies
2080 West Mall, University of British Columbia
Vancouver, BC V6T 1Z2
CANADA
clrs@interchange.ubc.ca

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Introduction

In Canada, there are about 44,770 adults between the ages of 45-64 years and 11,080 adults over the age of 65 years living with a developmental disability.[1] Some people are not known to <u>formal service providers</u>* (agencies or organizations that help and support individuals with developmental disabilities and their families). There are different ideas about the age at which a person is called a "senior". For these reasons, it is hard to know exactly how many aging adults with developmental disabilities exist.

Literature (books and articles) on the topic of seniors with developmental disabilities is difficult for a number of reasons. One reason is that different definitions of "senior" and "old age" are used across research studies. Also, some research classifies people as young as 40 years as "seniors". There is some agreement in the disability community that an individual with a developmental disability who is 50-55 years of age is considered a senior.

Another reason that makes this area difficult is that people with Down Syndrome usually begin to experience age related health problems at an earlier age than individuals with other types of developmental disabilities. Also, the <u>life expectancy</u>* (how long a person is expected to live for) for people with this type of disability is almost 10 years shorter than the life expectancy for individuals with other types of developmental disabilities.[2]

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[1] (Participation and Activity Limitation Study, 2001)
[2] (Janicki et al., 1999)

Similarly, the severity of disability influences (affects) <u>life expectancy</u>* with people with severe and profound disabilities usually dying younger than those with mild or moderate disabilities.[3] This creates further difficulty in researching this area as researchers exploring aging adults with developmental disabilities do not often make the distinction between adults with different levels of disability.

The <u>life expectancy</u>* of individuals with a disability continues to increase as health and living conditions continue to get better.[4] Supports and services for seniors with developmental disabilities and their families has become an important issue.

People with and without disabilities share many concerns about aging. However, aging with a developmental disability is often complicated because generally they:

- Are more dependent on caregivers,

- Generally have less income (money),

- Have fewer opportunities to make choices, and

- Have less knowledge of possible options.[5]

Many adults with developmental disabilities want to continue to participate in meaningful activities as they get older.[6] However, much of the activities older adults participate in are leisure-related (for example, watching television, relaxing, reading, spending time alone).[7]

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[3] (Rice and Robb, 2004)
[4] (Delorme, 1999; Heller, 1999; Rice & Robb, 2004; Salvatori et al., 1998)
[5] (The American Association on Mental Retardation, p. 2-3)
[6] (Bigby, 2004)

Disability System vs. Aging System

Who is responsible for helping people who are both seniors and living with a developmental disability? Support for people with developmental disabilities has been provided by the disability system. However, once these people are considered seniors, what role does the aging system play in providing service?

Generally in B.C. when a person is <u>incapacitated</u>* (helpless; when you can't do all the things you used to be able to do like walking or remembering things), needing extended, complete long-term care, the aging support system and health care support system become responsible for supporting these older adults. Before this, Community Living BC (disability system) is the <u>funding body</u>* (the organization that provides the money) responsible for such support.

It has been suggested that the disability system views the aging system as offering new and exciting opportunities for supporting aging adults with developmental disabilities.[8] However, some people believe that the aging system sees the inclusion of individuals with disabilities into this system as a failure. Such perspectives are a problem because aging adults likely face difficulties in receiving proper and necessary care and support.

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[7] (Salvatori et al., 2003)
[8] (Ansello, 2005)

The National Advisory Council on Aging, Canada (2004) has stated that co-operation among the disability and seniors sectors is not taking place because of:

- Limited resources (not enough money and staff support) and

- A lack of knowledge and expertise with regard to seniors and disability.

> "Being a part of the community includes being able to get good service from systems set up to support those who need them. For aging adults with developmental disabilities, this includes seniors groups, home care, and the health care systems."[9]

The question of what role each system plays is important for the proper care of these aging individuals.

Family and Friends: Informal Supports

Informal care* (unpaid support and assistance usually provided by family and friends) is a main area of support for aging adults with developmental disabilities.[10] Research tells us that the family offers the most and the most regular support to older adults with developmental disabilities. This is especially true in the area of residential settings (living arrangements).[11]

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[9] (Biersdorf, 2000)
[10] (Bigby, 2000)
[11] (Braddock, 1999; Heller, 1997; Shrestha & Weber, 2002)

Self-advocates* (adults with developmental disabilities) have explained that relationships with others was important in living healthy and satisfying lives.[12] As they get older, many self-advocates* worry about:

- Isolation,

- Loneliness, and

- A general lack of relationships.

Many adults live with their aging parents.[13] Such living arrangements can be challenging because aging parents are faced with their own health issues. The large role in care-giving provided by parents in the lives of many older adults with disabilities can be difficult when a parent becomes incapacitated* or dies.[14] For many older adults, the loss of parents means a new person needs to help make sure people get the support they need.[15]

Later-life planning (planning for one's future)[16] is a tool used to make sure the needs and desires of self-advocates* will be met. Areas to plan for include:

- Accommodation (living arrangements),

- Finances,

- Leisure,

- Social networks and community participation, and

- Health.

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[12] (Crawford, 2004)
[13] (Braddock, 1999)
[14] (Bigby, 2000)
[15] (Bigby, 2004)
[16] (Sterns et al., 2000)

Parents report that future planning about the living arrangements for their adult child is one of the most difficult decisions.[17] Parents worried that government funding would not continue to be available to maintain the lifestyle of their children. Research has found that many parents have not done any future planning for their adult child.

For many <u>self-advocates</u>*, living with parents can mean a protected life; opportunities to build relationships and networks with people other than the family may not be encouraged.[18] Many older <u>self-advocates</u>* have a range of positive experiences after moving out of the family home.[19] For some, this is a time of new experiences and opportunities as these individuals leave the child role to step into the adult role. Research found that some new carers (person providing care):

- Encouraged skill development,

- Looked for opportunities for social contact, and

- Encouraged participation in new and different experiences.[20]

Programs and Services: Formal Support

Formal (paid and organized) and <u>informal support</u>* are linked and offer complementary (balancing) support. Formal support staff play an important role in supporting and encouraging informal relationships (friendships with unpaid people) in the lives of older adults with developmental disabilities.[21] Service providers need to recognize and

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[17] (Freedman et al., 1997)
[18] (Bigby, 2000; Bigby, 2004)
[19] (Bigby, 1997)
[20] (Bigby, 1997)
[21] (Bigby, 2004)

appreciate that aging parents of adults with developmental disabilities are a huge resource.[22] Parents provide many decades of unpaid support.

Supports and services are a necessary part of life for many <u>self-advocates</u>*. Supports can play a part to improve <u>quality of life</u>* (overall enjoyment of life). However, research explains that the disability system has not supported aging people in the past.[23] This is because people with developmental disabilities are living longer.

Service providers were surveyed and stated that their services were inadequate to support these older adults.[24] In order to better support these adults, service providers recommended:

(1) Provide training to staff and professionals,

(2) Apply strategies to offer additional counselling support to elderly adults with developmental disabilities specifically in the area of loss and grief, and

(3) Identify and apply strategies to improve service provider partnership.

Residential Options

Aging adults with developmental disabilities may live in a variety of residential settings (living situations; for example, group homes, family home, supported living unit). Limited choices are available in Canada. Also, there are long waiting lists and some are inappropriately designed to meet specific needs.[25]

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[22] (Seltzer et al., 1997)
[23] (Janicki, 1999)
[24] (Sparks et al., 2000)
[25] (National Council on Aging, 2004)

Older adults reported that desirable living arrangements included:

- Living with friends,

- Having pets,

- Having a garden,

- Being involved in the housework,

- Having some control over their home environment (e.g. choice about where they live, choice about who they live with),[26] and

- Having opportunities to participate in activities and independence.[27]

Having family as a regular part of their lives was also important for older adults living outside the family home.

Research identified three main categories of housing options for aging individuals with a developmental disability.[28]

(1) _Semi-independent_ or _supported living_* is independent housing in the community with a separation of housing and support (for example, help with meal preparation, household chores).

(2) _Communal living_* refers to living in a room in a building with others with partial combination of housing and support.

(3) _Group living_* may be small (3-10 people) or large (10-60+ people) congregate living with a full combination of housing and support (examples of this housing option include group homes or boarding homes).

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[26] (Thompson, 2002)
[27] (O'Rourke et al., 2004)
[28] (Bigby, 2004)

Findings from a study with older adults with developmental disabilities suggested that generic aged residential environments* (living situations for older adults both with and without disabilities, for example, nursing homes):

- Promote dependence,

- Provide inadequate stimulation,

- Consist of people much older than the people with the developmental disability, and

- Have staff who do not understand the needs of this adult population.[29]

Those adults who live in supported accommodation or other independent options generally have larger networks made up of more friends and less family members.[30]   This is compared to older adults who live in the family home.

As individuals get older, their needs change and the family may no longer be able to provide all the required care.   How can individuals and families be supported so that individuals can remain in a home in the same community without being transferred to a new location?

The British Columbia Association for Community Living (BCACL) has an "Aging in Place Policy"; this policy states, "When an older adult's health status changes, every attempt should be made to accommodate the changing needs of aging adults…Resources should be made available to accommodate an adult staying in their home for as long as possible." (p. 2).

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[29] (Bigby, 1997; Hatzidimitriadou & Milne, 2005)
[30] (Bigby, 2004)

Work and Retirement

Vocational activities (work and employment activities) have been a part of the lives of many individuals with developmental disabilities.[31]

Work provides opportunities for:

- Social interactions,

- Network building,[32] and

- The development of a sense of purpose and self worth.[33]

Research[34] tells us that people with a disability often leave the workforce completely at the age of retirement.[35] However, some aging self-advocates* may wish to continue to work beyond "retirement age".[36]

Day Programs

Day programs are an appropriate support for many individuals with developmental disabilities. Recreation and leisure opportunities add to high quality of life*.[37] However, for some adults with developmental disabilities, leisure activities (activities done during free time) are mostly inactive activities such as watching television and listening to the radio.[38]

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[31] (Wadsworth et al., 1995)
[32] (Salvatori et al., 1998)
[33] (Boyd, 1997)
[34] (Seltzer and Krauss, 1987)
[35] The age of retirement for individuals with developmental disabilities remains unclear. Sterns et al. (2000) assert that many American states recognize 55-60 years as the retirement age.
[36] (Delorme, 1999)
[37] (Boyd, 1997; Hoge & Wilhite, 1997)
[38] (LeRoy et al., 2004)

Research suggests and describes the *recreation integration process* as a tool for encouraging active leisure participation.[39]

Research in the area of day programs has identified three categories, they are:

(1) <u>*Age-integrated programs*</u>* (programs for people with developmental disabilities of all ages),

(2) <u>*Age-specific programs*</u>* (programs for people with developmental disabilities who are in a particular age category), and

(3) <u>*Generic integration*</u>* (programs for all older adults both with and without disabilities).[40]

One program in Australia, referred to as the "age-integrated specialist brokerage program", is managed by the state government. This program "…supports people with disabilities on the basis of their individual needs and is not limited by the existing service models."[41] The program:

- Worked to maintain and encourage social networks,

- Encouraged participation in a wide range of activities, and

- Provided funding for identified support (up to $5000).

<u>Age-integrated programs</u>* in general offered individual planning rather than group planning. Also, planning was not limited by facilitators' ideas of enjoyable or appropriate

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[39] (Hoge & Wilhite, 1997)
[40] (Bigby, 2005)
[41] (p. 79)

programs for older people. The age-specific programs* made use of limited planning which focused only on the time the individual spent at the centre. Also, planning involved only those programs available through their agency.

Some researchers suggest accessing resources and support available in the larger community outside of the disability system.[42] For example, drop-in recreation centres for people who are retired or who work only part-time. Existing community services may also offer home support or opportunities to connect older individuals with and without disabilities. Extra training and education for service providers in aging and disability systems may help aging adults with developmental disabilities successfully access generic integration programs*.[43]

Grief and Loss

Both aging adults with developmental disabilities and service providers identify grief and loss as an important issue in the lives of these older adults.[44] Aging people may experience many types of loss (for example, the loss of a parent, loss of a home or job).[45]

Service providers admit to a service gap in the area of grief and loss and have requested training to better support aging adults in this area.[46] Grief support can include education and looking at other life changes. Support workers must be aware of and have respect for

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[42] (Janicki, 1999)
[43] (Bigby, 2005)
[44] (Crawford, 2004; Sparks et al., 2000)
[45] (Sterns et al., 2000).
[46] (Sparks et al., 2000)

the individual, cultural (religion, different languages, ethnicity), family, and social values that are important to the individual.[47]

Assistive Technology and Environmental Interventions

As self-advocates* get older, assistive technology* (any piece of equipment that is used to increase, maintain, or improve the functional capabilities of persons with disabilities)[48] and environmental interventions* (changes to an environment so that it meets the needs of an individual) may become important and useful tools for well-being. Research has explored what assistive technology* and environmental interventions* meant in the lives of these individuals.[49] Participants reported increased ability to:

- Communicate,

- Get around,

- Participate in activities, and

- Connect with the community.

Seventy percent of participants indicated that their performance in life tasks was better when using assistive technology*.

Choice and Self-determination

Active choice making and focusing on personal preferences in planning for the future is important for supporting self-advocates*.[50] However, research has found that choice and

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[47] (Botsford, 2000)
[48] http://www.atia.org/about.html
[49] (Hammel et al., 2003)
[50] (Wadsworth et al., 1995)

decision-making is often not included in the lives of aging adults with disabilities.[51]   The National Advisory Council on Aging (2004) explained that the lack of decision-making opportunities for these individuals "…can create unnecessary dependency among those who do have the capacity for self-determination." (p. 9).

The training intervention in later life planning is a way to increase feelings of empowerment* (having the right to make one's own choices and of having the ability to act on them[52]) and choice in older adults.[53]   This intervention provides information and skill building with both individuals with developmental disabilities as well as service providers and families.

Innovative Approaches to Supporting Aging Adults with Developmental Disabilities

Around the world there are various examples of innovation (originality and improvement) in supporting this population. Some of the examples are listed below.

Intellectual Disability Database, Republic of Ireland. This database collects and organizes information about those individuals who are receiving or in need of services.[54]   The purpose of the database was to make sure that correct information about the needs of individuals with intellectual disabilities was available. This information was used to inform the planning and coordination of services.[55]

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[51] (Ashman and Suttie, 1995)
[52] www.lymphomainfo.net/lymphoma/glossary.html
[53] (Heller et al., 1996)
[54] (O'Grady Reilly & Concliffe, 2002)
[55] (Oasis, 2005)

Victoria Department of Human Services – Australia. The Victoria Department of Human Services recognizes that day support can take place outside the traditional hours (for example, outside of Monday-Friday, 9am-3pm) and can be located in the person's home, community, or day centre.[56] This means that day/residential/leisure services can be provided in a more flexible way.

Integrated Model of Service to Older Adults with Developmental Disabilities. This model was recommended as a way to address the challenges related to the separation of the disability system and the aging system.[57] The model involves collaboration (partnership), outreach (connecting with people and the community using different approaches), and capacity building. It stressed the importance of "top-down" and "bottom-up" tools for partnership (for example, state-wide and local-level approaches).

Coalition Building Forums, University of Georgia. The University of Georgia's University Affiliated Program for Persons with Developmental Disabilities became involved in a training project that addressed the training needs of personnel (workers or staff) in the aging and developmental disability fields while working in partnership.[58] "Coalition building forums" were held throughout Georgia to bring together self-advocates* and their families and aging and developmental disabilities personnel.

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[56] (Bigby, 2004)
[57] (Ansello and Coogle, 2000)
[58] (Smith & Thyer., 1997)

Options for Older Families. Australia introduced two pilot programs (test programs) which used an approach for supporting individuals in a way that prevents crises through continuous and active planning.[59] The goals of the pilots were to:

(a) Organize current services to allow "aging in place"* (living where you have lived for many years, or living in a non-healthcare environment, and using products and services to allow or enable you to not have to move as situations change),[60]

(b) Help families in effective future planning, and

(c) Help self-advocates* obtain skills.

The services were provided on a long term basis and intensive support provided based on individual client need.

Huron Trillium Partnership, Ontario. This partnership was a place where service providers could discuss issues related to aging and developmental disability.[61] It was also important to develop relationships between long-term care and developmental disabilities support systems. To form these relationships the following steps were taken:

- Publishing a newsletter to be distributed to agencies in both sectors,

- Hosting training workshops, and

- Developing guiding principles to help partners in such planning.

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[59] (Bigby et al., 2002)
[60] http://www.seniorresource.com/ageinpl.htm#place
[61] (Huron Trillium Partnership, d/u)

Recommendations for Future Practice

Partnerships across systems will enable aging adults with developmental disabilities to receive the most appropriate support as needed. Researchers have suggested that a "family lens" (consider the entire family rather than just the <u>self-advocate</u>*) be used by all levels of government to guide policy and by publicly funded services in the delivery of services.[62] Also, it is important that relationships with family and friends are maintained. Literature recommends that choice, self-determination, and active engagement be encouraged in the lives of these individuals.

Conclusion

This summary outlined the important issues when thinking about the lives of aging adults with developmental disabilities. Topics such as the service system, family and friends, living arrangements, retirement, day programs, grief and loss, <u>assistive technology</u>*, and choice and self-determination were briefly explored. Also, some supports and services available around the world designed to meet the needs of this population were described. Overall, this summary document provided a snapshot of what it means to be an aging adult with a developmental disability and how the needs and hopes of these individuals can be best supported.

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[62] (MacLellan et al., 2002)

Glossary

Age-integrated programs: are programs for people with developmental disabilities of all ages (mentioned on pages 15, 16).

Age-specific programs: are programs for people with developmental disabilities who are in a particular age category (mentioned on page 15, 16).

Aging in place: is living where you have lived for many years, or living in a non-healthcare environment, and using products, services and conveniences to allow or enable you to not have to move as circumstances change (mentioned on page 13, 20).[63]

Assistive Technology: is any item, piece of equipment, product or system, whether acquired commercially off the shelf, modified, or customized, that is used to increase, maintain, or improve the functional capabilities of persons with disabilities[64] (mentioned on pages 17, 21).

Communal living: refers to living in a room in a building with others with partial combination of housing and support (mentioned on page 12).

Empowerment: means having the right to make one's own choices and having the ability to act on them (mentioned on page 18).

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[63] http://www.seniorresource.com/ageinpl.htm#place
[64] http://www.atia.org/about.html

Environmental Interventions: are changes to an environment so that it meets the needs of an individual and helps the individual be successful in that environment (mentioned on page 17).

Formal service providers: are agencies or organizations that help and support individuals with developmental disabilities and their families (mentioned on page 5).

Funding body: is the organization that provides the needed money/funding (mentioned on page 7).

Generic integration: are programs for all older adults both with and without disabilities (mentioned on pages 15, 16).

Generic aged residential environments: are living situations for older adults both with and without disabilities; for example, nursing homes (mentioned on page 13).

Group living: may be small (3-10 people) or large (10-60+ people) congregate living with a full combination of housing and support (examples of this housing option include group homes or boarding homes) (mentioned on page 12).

Incapacitated: means helpless; when you can't do all the things you used to be able to do like walking or remembering things.[65] (mentioned on page 7, 9).

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[65] info.dhhs.state.nc.us/olm/manuals/dss/ei-30/man/FSx3300-01.htm

Informal care or support: is unpaid support and assistance usually provided by family and friends (mentioned on pages 8, 10).

Life expectancy: is how long someone is expected to live (mentioned on pages 5, 6).

Self-advocates: are, for the purposes of this report, adults with developmental disabilities (mentioned on pages 9, 10, 11, 14, 17, 19, 20, 21).

Semi-independent **or** ***supported living:*** is independent housing in the community with a separation of housing and support (for example, help with meal preparation, household chores) (mentioned on page 12).

Quality of life: is one's overall enjoyment of life (mentioned on pages 11, 14).

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