Residential Options for Adults with Developmental Disabilities: Quality and Cost Outcomes

A Plain Language Summary

Reading this report

This paper is a plain language report adapted from a full academic/government report called "Non-residential Supports and Intellectual Disability: A Review of the Literature on Best Practices, Alternatives, and Economic Impacts" 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.

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Introduction

Recent movement toward inclusion and <u>self-determination</u>* (having independence and making one's own decisions) have resulted in a shift in residential values reflecting choice, community living, and active participation. With this shift in values came different types of living options; for example, life sharing and semi-independent living. Research has begun to look at these options in terms of cost and quality outcomes (results). Many positive quality outcomes related to <u>residential alternatives</u>* (different kinds of places people with developmental disabilities can live, not including group homes) have been identified.

However, study in this area for adults with severe developmental disabilities is limited. Housing options for these adults are often restricted to institutional environments.

In general, research has found that residential options that encourage <u>quality of life</u>* (overall enjoyment of life) have the following description:

- Are similar to family homes,

- Are in communities where individuals have a social network (relationships with people you spend time with), and

- Have well-organized and directed levels of support.

Trends in Residential Options

In Canada, the number of people with developmental disabilities living in institutional settings has declined considerably in the past twenty years.[1] According to Community Living British Columbia, most adults with a developmental disability living in B.C. live in family model homes (when an individual with a developmental disability lives with a roommate or a non-relative family in a home that is owned or rented by the family or the individual) or non-profit group homes.[2] Other residential arrangements (in order of most to least people living in these settings) are:

- Staffed for-profit group homes,

- Adult semi-independent living (for example, apartments with support available if needed),

- Microboard services – residential, and

- Intensive adult care services (for example, a seniors home).

Over the last 25 years, residential services for self-advocates* (adults with developmental disabilities) have also changed considerably in the United States.[3] The number of individuals with developmental disabilities living in institutions decreased and the number of individuals living in group homes

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[1] (Braddock et al., 2001; Crawford, 1996; Pedlar et al., 2000; Taylor, 2001)
[2] The Adult Services Regional Quarterly Report, 2006
[3] (Braddock et al, 2001; Lakin et al., 2003)

increased.[4]   Also, increasing numbers of individuals were living in group homes with a smaller amount of people (under 6).

Self-advocates* in the U.S. were living in the following settings (most to least):

- Group homes,

- Supported apartments,

- Foster family care,

- Natural parents,

- Houseparent homes, and

- Boarding homes.[5]

Movement away from institutional living also took place in the United Kingdom and Australia. Research found that more individuals in Australia were living in group homes and institutions than in Canada.[6] Also, less people in Australia were living in semi-independent settings compared to Canada.[7] Compared to the U.S. and the U.K., Australia provided less government funded (paid for by the government) residential services for self-advocates*.[8]

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[4] (Lakin et al., 2003)
[5] (Braddock et al., 2001)
[6] In British Columbia, all institutions were closed by 1996.
[7] (Braddock et al., 2001; Stancliffe, 2002)
[8] (Stancliffe, 2002)

Key Terms

The types of residential options that will be explored in this summary are:

(a) *Group homes*: a staffed home (employees work in the home providing support to the people living there) in the community for groups of individuals to live. Staff support is in the home 24 hours a day assisting individuals with personal care, meal preparation, etc.;

(b) *Cluster housing*

    (i)   *Campus type living* – is when individuals live close to each other and form a separate community from the surrounding community.

    (ii)   *Village communities* – are "…a cluster of living units and other resources (e.g. day centers, shops, churches) that are physically segregated from the local community."[9]

(c) *Supported living*: is a model in which an individual, who lives mostly independently, and receives only those supports he/she requires;[10]

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[9] (Emerson et al., 2000, p. 83)
[10] (Hewitt & O'Nell, 1998)

(d) *Semi-independent living services:* provides support for <u>self-advocates</u>*

who live for the most part independently and receive a limited amount of

hours of services each week from paid staff;

(e) *Family model home/ life sharing/ host family/ foster care:* is when a <u>self-advocate</u>* lives with a roommate or a non-relative family in a home that

is owned or rented by the family or the <u>self-advocate</u>*; care and support

is provided by the roommate/family;[11]

(f) *Family home/ family support*: "A home owned or rented by a family

member…in which the individual with ID/DD [intellectual

disability/developmental disability] resides and in which the individual

receives care, instruction, supervision and other support from persons

other than family members and/or from family members who are paid";[12]

and

(g) *Home ownership.*

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[11] (Bruininks et al., 2005, p. 71)
[12] (Bruininks et al., 2005, p.71)

Limitations to Group Homes

Group homes continue to lead as the standard model of care for self-advocates* in the U.S.,[13] Australia, and Canada[14]. Group homes can be small or large depending on the number of people living within the home. Research has found that people living in small group homes did better than people living in large group homes.[15] Features of small group homes that made for better results included:

- Larger social networks* with more people who were not staff or family,

- Social networks* that were made up of fewer individuals with a disability, and

- Higher numbers of unpaid social support.

However, many problems have been connected to group home arrangements. These problems include:

- Inflexible schedules (i.e. everyone has to follow the set schedule for that group home, choice is absent or limited),

- High levels of staffing (i.e. there are more than necessary staff members),

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[13] (Stancliffe, 2005)
[14] (Braddock et al., 2001; Taylor, 2001)
[15] (Emerson et al., 2001)

- Incompatibility and arguments among residents (i.e. residents might not get along),

- Inability to adjust to residents' changing needs/preferences, and

- Low levels of personal choice and autonomy (independence) regarding group activities and decisions.[16]

Research suggests that some individuals living in group homes do not need such high levels of support. In fact, some people may experience "…better outcomes, at lower cost, by living semi-independently".[17]

It will be increasingly important to be able to successfully support adults with developmental disabilities as the demand for Community Living arrangements in the next 10 years rises. Reasons for this increased demand include an:

- Increased number of <u>self-advocates</u>* from the baby boom generation (people born between 1945-1960) who are cared for by elderly parents,

- Increased life expectancy (how long a person is expected to live) and lower mortality (death) rates, and

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[16] (Emerson et al., 2001; Howe, Horner & Newton, 1998; Stancliffe, 2005; Stancliffe & Keane, 2000)
[17] (Stancliffe & Keane, 2000, p. 302)

- Increased survival rates of young people with severe and complex disabilities.[18]

Residential Alternatives:

Severe Developmental Disability and Serious Challenging Behaviour

Not very many studies have looked at the costs and benefits of various housing options for adults with severe developmental disabilities. Generally, deinstitutionalization and residential living has been challenging for these individuals.[19] These people are:

- More likely to be institutionalized,

- Less likely to be offered residential services until the end of the deinstitutionalization process, and

- More likely to be reinstitutionalized or sent to other institutions.[20]

Also, they:

- Are at increased risk of abuse,

- Live in restricted and depressing environments,

- Receive very little staff contact,

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[18] (Emerson, 1999)
[19] (Felce et al., 1998; Mansell et al., 2001)
[20] (Mansell et al., 2001)

- Remain isolated from the community and personal <u>support networks</u>*, and

- Receive little help dealing with challenging behaviour.[21]

Limited research has been done to look at alternatives to institutional living for adults with severe developmental disabilities. Some specific efforts have been taken to move individuals with severe disabilities and problem behaviours from institutions into supported living settings. These efforts took place over a 4 year period and were researched.[22] This process involved creating detailed support plans with a range of support strategies focusing on community integration, <u>social network</u>* development, and problem behaviour management. Overall, the research that looked at these efforts found many positive results; for example:

- Some problem behaviours decreased,

- Participation in social and inclusive activities increased, and

- Costs were similar to costs of support in institutions.

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[21] (Felce et al., 1998; Mansell, et al., 2001)
[22] (Horner et al., 1996)

In another project, researchers formed a Special Development Team.[23] This team helped local services create individualized placements and develop the capability to care for severely challenging individuals within the community. The purpose of this team was to make sure these individuals had a good quality of life* despite their level of challenging behaviour.

Individuals were placed in specialized staffed houses (defined as houses or apartments) with an average of 3 people per placement. Results showed that the cost of the specialized residential placements was much more than ordinary staffed housing services; however, the specialized residential placements were similar in cost to specialized institutional placements.[24]

Quality of life* results showed that, once people moved to staffed houses, they showed an increase in:

- Their overall participation in meaningful leisure, personal, and practical activities,

- Participation in general activities which meant less time doing sedentary (inactive – sitting around) activities, and

- Skills and competence (ability).

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[23] (Mansell et al., 2001)
[24] (Mansell et al., 2001)

However, social interaction (relationships with housemates) within the houses was difficult and did not show an increase.

In a similar study, researchers compared the costs and results of different service models (ways of supporting people) for individuals with severe disabilities and challenging behaviour.[25] These service models included family homes, hospitals, hostels and community housing (group homes). Results were more positive for those individuals residing in a community house when compared to the other service models. Positive results were:

- More individual support from staff,

- Involvement in more daytime activities, and

- Higher levels of autonomy (independence) and social interaction.

Residential Alternatives to Group Homes: Research Findings

Cluster Housing

Research in the U.K. compared the quality and costs of cluster housing to dispersed (spread out) housing. Findings showed that cluster housing was associated with a poorer quality of care and a poorer quality of life*.[26]

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[25] (Felce et al., 1998)
[26] (Emerson, et al., 2000; Emerson, Robertson, Gregory, Kessissoglou, Hatton & Hallam et al., 2000)

Supported Living

Studies looking at supported living indicated that individuals in supported living arrangements experienced more social and community based activities than individuals receiving traditional services (e.g. group homes). Costs for supported living and traditional services were similar.[27] Other positive outcomes related to supported living included:

- Receiving more staff support,

- Having housemates consistent with preferences (likes and dislikes), and

- Being the decision-makers in daily life.[28]

Supported living arrangements also had better processes for distributing support staff based on the need of those living in this arrangement.[29]

However, other research found that people in supported living had:

- Fewer planned activities,

- Higher rates of home vandalism, and

- Greater risk of mistreatment.[30]

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[27] (Howe et al., 1998)
[28] (Howe et al., 1998)
[29] (Emerson et al., 2001)
[30] (Emerson et al., 2001)

KeyRing Support Network

In England and Scotland there are "living support networks" which help individuals with developmental disabilities to live in their own homes in their own communities.[31] KeyRing (www.keyring.org) is the support service in England. This "...unique system of support was designed to make the best use of network member's own abilities. Ten ordinary properties are scattered around a small neighbourhood within walking distance of one another. Nine flats or houses belong to people with learning disabilities…The tenth is occupied by the Community Living Worker (CLW) who works part time on a flexible basis."

KeyRing is evaluated every three years. The most recent findings showed that KeyRing performs well overall and performs better than many other organizations.[32] KeyRing is also strong in the areas of community building, independence, and involving KeyRing members.

Semi-independent Living

Researchers compared outcomes (results) and costs associated with group homes and semi-independent living for self-advocates* in Australia.[33] They concluded that group homes were less cost effective (cost more for what you

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[31] (Neighbourhood Networks, 2006)
[32] (KeyRing Living Support Networks, 2006)
[33] (Stancliffe & Keane, 2000)

get) than semi-independent services. Also, people in semi-independent settings had similar or better quality of life* outcomes even though they received less staff support and cost less.

Choice in Living

An example of semi-independent living in Australia is the Choice in Living (CIL) residential program. Choice in Living is a new program in Victoria and "…offers local people…with disabilities, the chance to live how, where and with whom they choose, and assists them to work towards the things in life that are important to them. CIL enables people to remain in the community where they…[already have] relationships and community ties, after their families are no longer able to support them in the family home."[34]

Life Sharing

The term "life sharing" refers to a planned coming together of individuals committed to sharing their lives, or a portion of their lives, with one another. Life sharing is an innovative (new and original) term gaining popularity in B.C. Although this type of residential arrangement for self-advocates* has existed for years, there has not been much research in the area.

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[34] (Accessed September 1, 2006,
http://hnb.dhs.vic.gov.au/ds/disabilitysite.nsf/sectionthree/accomm_innovation_grants?open#cil)

The limited research suggested that the number of people participating in life sharing services is gradually increasing.[35] Some research also suggested that adults who previously lived in institutions or group homes and who were placed in life sharing settings were experiencing positive changes.[36]

Co-housing

Co-housing incorporates <u>strata title home ownership</u>* (a property owner owns his or her unit and a part of the common areas of the site)[37] "…in an environment where all owners want to be in relationship with their neighbours and live in a more supportive and cooperative environment".[38] Home owners are involved in the planning, design, management and maintenance of the community.[39] Over 40 co-housing communities have been created in the U.S. and Canada with hundreds more in various stages of development.

Co-operative Housing

Co-operative housing is a type of <u>subsidized housing</u>* (housing supported by the government so that people with low incomes can afford housing) with fixed (unchanging) rent. This type of housing is available to "…frail seniors, people

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[35] (Bruininks et al., 2005)

[36] (Walling et al., 2000)

[37] http://www.city.vancouver.bc.ca/COMMSVCS/developmentservices/subdivision/stratatitle.htm

[38] (Planned Lifetime Advocacy Network, 2006, p. 4)

[39] (Canadian Cohousing Network)

at risk of homelessness, people with disabilities, and low-income families, including women and children fleeing abuse."[40]

Home Ownership

According to Planned Lifetime Advocacy Network (PLAN)[41], home ownership has many advantages. There is status and pride associated with owning a home. An owner has control over buying and selling a home. The potential owner also has control over the type of home they purchase and where it is located. There is stability and security associated with home ownership. Also, a home is a good investment that can accumulate (grow) in value. With home ownership an individual has greater influence and control over roommate choice and length of stay.

Vulnerability, disability benefits, taxes, financing, competency, support services, and monitoring are considerations for potential home owners.

There are many types of ownership (for example, full ownership, joint tenancy, home owned by a trust).

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[40] (BC Housing, www.bchousing.org)
[41] (2006, www.planinstitute.ca)

Residential Alternatives and Canada

Nova Scotia started the Community Supports for Adults Renewal Project to review the Community Supports for Adults program. The purpose of the project was to learn ways of improving support services for <u>self-advocates</u>*.[42] Out of the project, three new programs were initiated (started):

- Supported Apartments,

- Alternate Family Support (Life Sharing), and

- Direct Family Support.

Ontario offers a number of accredited Community Living support services for people with disabilities. For example, Avenue II provides individualized support based on clients' personal wants and needs to make it possible for <u>self-advocates</u>* to live independently in their own homes.

In *British Columbia*, the Burnaby Association for Community Inclusion (BACI) introduced the Life Sharing Network. BACI currently receives funding from Community Living British Columbia (CLBC) to help with the costs of life sharing for 29 <u>self-advocates</u>*.

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[42] (Nova Scotia Community Services, 2005)

BC Housing (www.bchousing.org) offers subsidized housing* to people with disabilities who qualify for the Independent Living BC Program. This program offers an alternative to home care and residential care for people who need some assistance but don't want or need 24-hour care.

The Vela Microboard Association (www.microboard.org) is "…dedicated to exploring, facilitating [assisting], and supporting innovative community living options for people with disabilities…Vela Microboard Association strives to develop and support living options that facilitate true interdependence, integration, and membership in the community." Vela also has affiliates (partners) in other parts of the world (Northern Ireland and southwest Virginia). According to CLBC[43], 81 adults with developmental disabilities in British Columbia use their microboard to make residential arrangements.

Conclusion

Recent trends placing importance on inclusion and self-determination* have resulted in a shift in residential values. With this shift came residential alternatives* to group homes such as life sharing and semi-independent living. Research has begun to look at these alternatives and has identified many

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[43] Adult Services Regional Quarterly Report (2006)

positive quality outcomes associated with <u>residential alternatives</u>*. Some of these outcomes included:

- Increased choice,

- Greater <u>empowerment</u>* (having the right to make one's own choices and having the ability to act on them), and

- Individualized support.

Some poor results attached to these residential options have also been identified in recent research. The main challenge of these alternatives is the potential for social isolation because there are less planned activities. However, an awareness of the challenges is useful because planning can be focused on reducing or removing challenges and barriers to <u>quality of life</u>*.

Residential services will be in increasing need for:

- Middle aged adults (baby boom generation),

- Older adults (because of increased life expectancy), and

- Young adults with severe disability (because more are living now with better medical care than when they were born).

This area of service and support needs serious study. There also needs to be many options to meet the different needs of this individualized population. If we are aware of and understand the positive and negative <u>quality of life</u>* and cost outcomes then we are better able to plan. In general, research has found that residential options that encourage <u>quality of life</u>* have the following descriptions:

- Are similar to family homes,

- Are in communities where individuals have a <u>social network</u>*, and

- Have well-organized and directed (focussed) levels of support.

Finally, it is important to note the limitations and gaps (missing pieces) in the current research. It is difficult to compare parts of the world because there are differences that get in the way of clear comparisons. Also, there is much research comparing institutional settings to community settings; however, there is not a lot of research comparing different community settings. Because there are no longer institutions in B.C., research studying institutions is not particularly useful. Few studies have reliably been able to capture this complexity.

Also, we cannot assume that because one example of a model shows good outcomes that all examples will show good results. Programs and models

vary (are different) in the way that they are operated and in the way they meet the needs of those people receiving support. For example, a small life sharing option with good quality controls may be different than a simple family placement with few planning or support features.

Glossary

Empowerment: means having the right to make one's own choices and having the ability to act on them (mentioned on page 24).

Quality of life: refers to one's overall enjoyment of life (mentioned on pages 6, 15, 16, 19, 24, 25).

Residential alternatives: are different kinds of places people with developmental disabilities can live, not including group homes. For example, supported living, family model homes, life sharing (mentioned on pages 6, 23,, 24).

Self-advocates: are, for the purposes of this report, adults with developmental disabilities (mentioned on pages 7, 8, 10, 11, 12, 18, 19, 22).

Self-determination: refers to having independence and making one's own decisions (mentioned on pages 6, 23).

Strata title home ownership: is where a property owner owns his or her unit and a share (part) of the common areas of the site.[44] (mentioned on page 20).

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[44] http://www.city.vancouver.bc.ca/COMMSVCS/developmentservices/subdivision/stratatitle.htm

Subsidized housing: is housing supported by the government so that people

who don't make a lot of money can afford housing (mentioned on page 20, 23).

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