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

Literature and Initial Program Review

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.

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Preface

This literature review was prepared by the Community Living Research Project and involved a search using electronic academic databases (i.e. EBSCOhost, Social Sciences Index) and the Google internet search tool. Key words used included: "developmental disabilit*", "intellectual disabilit*", "learning disabilit*", "residential options", "housing", "living", "supports", "services", "programs". More specific search terms were: group homes, cluster housing, foster families, supported living, semi-independent living.

Information was further collected through informal conversations with professionals in the field of developmental disability and those professionals associated with particular organizations and programs supporting individuals with developmental disabilities and their families. Members of the research team attended various seminars, workshops, and conferences from which information was also gathered.

Both the academic literature for the past 10 years and selected programs information on residential options for adults with developmental disabilities has been explored in this document. It should be noted that cross nationals comparisons must be read with caution given differing policy, wage and funding regimes. Much of the best literature compares institutional and community options which has limited utility in jurisdictions such as British Columbia. Comparatively, literature on different community options is sparse.

It is important to note that the program exploration is preliminary in nature. The specific programs outlined in the following pages are meant to highlight examples of residential options in practice. It is not meant to be exhaustive. A further and more detailed program review will follow at a later date.

Executive Summary

Recent trends emphasizing inclusion and self-determination have resulted in a shift in residential attributes reflecting choice, community living, and active participation. With this shift came residential alternatives to group homes such as life sharing and semi-independent living. Research has begun to explore these alternatives in terms of cost and quality outcomes and has identified many favourable quality outcomes associated with residential alternatives. However, exploration in this area for adults with severe developmental disabilities is sparse with housing options often limited to institutional environments. In general, research has found that residential options that resemble family homes and are located in communities where individual have a social network as well as well-organized and directed levels of support promote quality of life.

In Canada, people with developmental disabilities (DD) living in institutional settings has declined significantly in the past twenty years (Braddock et al., 2001; Crawford, 1996; Pedlar et al., 2000; Taylor, 2001). The Adult Services Regional Quarterly Report prepared by Community Living British Columbia (2006) indicates that the greatest percentage of adults with a developmental disability living in B.C. reside in the family home and group homes operated by the non-profit sector. Over the last quarter of a century, residential services for individuals with DD have changed substantially in the United States also (Braddock et al, 2001; Lakin et al., 2003). A decline in numbers of individuals with DD living in institutions was followed by an increase in the number of individuals living in group homes of varying sizes (Lakin et al.).

Similar to Canada and the U.S., trends representing a shift away from institutional living were also present in the U.K. and Australia. Research found that more individuals in Australia are living in group homes and institutions than in Canada[1] and less are living in semi-independent settings (Braddock et al., 2001; Stancliffe, 2005). Compared to the U.S. and the U.K., Australia allocated lower levels of government funded residential services for people with DD (Stancliffe). Stancliffe asserted that the differences in "residential provisions" were not a result of differences in the number of individuals with DD in these countries; instead, he explained, "…the lower availability of residential services in Australia appears to reveal a lower overall level of service to people with intellectual disability" (p. 122).

Much of the research exploring residential options for adults with developmental disabilities includes institutions as such an option. Research comparing the cost and quality outcomes of institutional living with those of community options is not particularly relevant to Canada and specifically, British Columbia. There are no more institutions in B.C. and the focus in residential

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[1] In British Columbia, all institutions were closed by 1996.

options has been on living arrangements beyond group homes. Thus, the research of particular interest is that discussing and exploring community options such as supported living or life sharing; however, research in these other options is limited.

The types of residential options that will be explored in this review are: (a) group homes, (b) cluster housing, (c) supported living, (d) semi-independent living services, (e) family model home/ life sharing/ host family/ foster care, (f) family home/ family support, and (g) home ownership.

Group homes continue to dominate as the standard model of care for people with DD in the U.S. (Stancliffe, 2005), Australia, and Canada (Braddock et al., 2001; Taylor, 2001). In an exploration of small and large group homes, Emerson et al. (2001) found residents in the former faired better than residents in the latter. Features of small group homes that contributed to this outcome included having: larger social networks with more people who were not staff or family, social networks that were comprised of fewer individuals with DD, and higher numbers of unpaid social support.

However, multiple problems have been associated with group home arrangements regardless of their size; these include: inflexible schedules, high levels of staffing, incompatibility/disputes among residents, inability to adapt to residents' changing needs/preferences, and low levels of personal choice and autonomy regarding group activities and decisions (Emerson et al., 2001; Howe, Horner & Newton, 1998; Stancliffe, 2005; Stancliffe & Keane, 2000). Research indicates that some individuals residing in group homes do not require such high levels of support and may demonstrate "…better outcomes, at lower cost, by living semi-independently" (Stancliffe & Keane, p. 302).

The ability to effectively support adults with developmental disabilities will be increasingly important as the demand for Community Living arrangements in the next decade rises. Demographic factors that contribute to this demand include an increased prevalence of people with developmental disabilities from the baby boom generation who are currently cared for by elderly parents, increased life expectancy and lower mortality rates, and increased survival rates of young people with severe and complex DD (Emerson, 1999).

Few studies have examined the costs and benefits of various housing options for adults with severe developmental disabilities. Generally, deinstitutionalization and residential living has proven problematic for these individuals (Felce et al., 1998; Mansell et al., 2001). According to Mansell et al., these individuals are more likely to be institutionalized, less likely to be offered residential services until the end of the deinstitutionalization process, and are more likely to be reinstitutionalized or sent to other institutions. Furthermore, they are at increased risk of abuse, live in restricted and bleak environments, receive very little staff contact, remain isolated from the community and personal support networks, and receive little help addressing challenging behaviour (Felce et al.; Mansell, et al.).

Limited research has been conducted to explore alternatives to institutional living for adults with severe developmental disabilities. Some research has examined efforts to move such adults into supported living environments and other community settings (see Horner et al., 1996; Felce et al., 1998; Mansell et al., 2001). Results demonstrated that the costs of the specialized residential placements were much more expensive than ordinary staffed housing services but were comparable to specialized institutional placements (Mansell et al.). Quality of life outcomes showed that participants showed a statistically significant increase in their overall participation in meaningful leisure, personal, and practical activities which led to more participation in activities, less sedentary behaviour, and an increase in skills and competence. However, social interaction within the houses was challenging and remained at low levels.

Residential Alternatives to Group Homes: Research Findings.[2]

Cluster housing: Research in the U.K. compared the quality and costs of cluster housing to dispersed housing and found that cluster housing was associated with a poorer quality of care and a poorer quality of life (Emerson, et al., 2000).

Supported living: Studies exploring supported living indicated that individuals in supported living arrangements experienced social and community based activities to a greater extent than individuals receiving traditional services even though costs were similar (Howe et al., 1998). Other favourable outcomes associated with supported living included receiving more staff support, having housemates consistent with preferences, and being the decision-makers in daily affairs. However, Emerson et al. found that supported living residents had fewer planned activities, higher rates of home vandalism, and greater risk of mistreatment. KeyRing Support Networks (www.keyring.org) in England and Scotland is an example of supported living.

Semi-independent living: Stancliffe and Keane (2000) found that, in comparison to semi-independent living, group home residents did not obtain better scores on any measured outcomes. In addition, semi-independent residents had similar or better quality of life outcomes even though they received less staff support at less cost. Choice in Living is an example of semi-impendent living options in Australia.

Life Sharing: The term "life sharing" refers to a planful and deliberate coming together of individuals committed to sharing their lives, or a portion of their lives, with one another. Although this type of residential arrangement for adults with DD has existed for years, there has not been much research in the area. The limited research indicates that adults who previously resided in institutions or group homes and who were placed in life sharing settings are experiencing positive changes (Walling et al., 2000).

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[2] See table 2, page 38 for a review of the favourable and unfavourable outcomes associated with each alternative.

Co-housing: Co-housing incorporates strata title home ownership "…in an environment where all owners want to be in relationship with their neighbours and live in a more supportive and cooperative environment" (Planned Lifetime Advocacy Network, 2006, p. 4). Home owners are involved in the planning, design, management and maintenance of the community (Canadian Cohousing Network, 2004).

Co-operative Housing: Co-operative housing is a type of subsidized housing with fixed rent that is available to "…frail seniors, people at risk of homelessness, people with disabilities, and low-income families, including women and children fleeing abuse." (BC Housing, www.bchousing.org).

Home Ownership: According to Planned Lifetime Advocacy Network (2006, PLAN, www.planinstitute.ca), home ownership has many advantages such as status and pride, control over buying and selling, stability and security, and an individual has greater influence and control over roommate selection and length of stay. Vulnerability, disability benefits, taxes, financing, competency, support services, and monitoring are considerations for potential home owners.

Residential Alternatives and Canada. *Nova Scotia* initiated the Community Supports for Adults (CSA) Renewal Project to review the Community Supports for Adults program. The purpose of the project was to discover ways of improving support services for people with disabilities (Nova Scotia Community Services, 2005) which resulted in the initiation of: 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 (d/u) provides individualized support, based on clients' personal wants and needs, to make it possible for individuals with DD to live independently in their own homes. In *British Columbia*, the Burnaby Association for Community Inclusion (BACI) introduced the Life Sharing Network. BC Housing (www.bchousing.org) offers subsidized housing to people with disabilities who qualify for the Independent Living BC Program. The Vela Microboard Association (www.microboard.org) is "…dedicated to exploring, facilitating, 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."

In this review. This document reviews the current literature on the costs and benefits of residential alternatives to group homes for people with DD. Findings from Canada, the United States, the United Kingdom, and Australia will be discussed in order to understand the world context in the area of residential alternatives. Cost and quality outcomes will also be explored. A specific investigation of research in the area of residential options for adults with severe DD will be highlighted. Finally, some residential options available throughout parts of Canada will be briefly discussed.

A.   **Introduction**

This paper reviews the current literature on the costs and benefits of residential alternatives to group homes for people with developmental disabilities (DD). Findings from Canada, the United States, the United Kingdom, and Australia will be discussed in order to understand the world context in the area of residential alternatives. The arrangements of particular interest include family care model homes, semi-independent living, and supported living. Historically institutions and group homes were the dominant residential settings for individuals with DD. However, recent trends such as normalization and more recently inclusion and rights have resulted in a shift in residential characteristics reflecting choice, community living, and active participation.

Cost and quality outcomes will also be explored. According to Stancliffe and Lakin (2005), "costs" refers to expenditures for services as well as the consideration of those processes for distributing resources that influence the type of service systems and how these systems function. Furthermore, all that is included in costs has direct implications for the lives of service recipients. Stancliffe and Lakin also assert that the main goal related to community services and expenditures is to effectively create high quality of life and high-quality outcomes. "Without satisfactory outcomes, expenditures on services are a poor investment for society, resulting in deprivation, increased disability, and even danger for service recipients and their families" (p. 2). Thus, economic concerns should not be the driving force for service planning and policy.

Underestimating the influence of costs and expenditures in the provision of services however, is not realistic either. Instead, an approach that appreciates and acknowledges both the cost and quality dimensions in order to identify the optimal living arrangement for people with DD is most practical.

> Service provision does have an important economic dimension, and it is essential to understand as much as possible the associations among service approaches, individual needs, costs, and outcomes so that effective, equitable, and economically sustainable service systems can be developed (Stancliffe & Lakin, 2005, p. 1).

This review begins by outlining various residential options present in the academic and grey literature. Next, trends in residential arrangements for individuals with developmental disabilities will be explored. It is important to make the distinction between residential approaches for supporting adults with

mild or moderate developmental disabilities and those approaches for supporting individuals with severe and profound disabilities. Literature exploring the latter is limited; available research on approaches in this area is discussed in this review. A deeper examination of various residential options, including quality and cost outcome data, takes place in Section H. Included in this examination is a closer look at various regions of Canada in terms of what is available. Overall, this review identifies and explores residential arrangements for adults with developmental disabilities within an international context.

B.   Literature Considerations

Literature in the area of residential options for adults with developmental disabilities is complicated by a number of factors. One issue concerns the disparity in term usage and the associated term definition. Different parts of the world make use of the same term but often in reference to a residential arrangement that varies from one part of the world to another and sometimes, from one study to another. This makes it difficult to compare findings across studies. Another similar challenge is the range of characteristics that define the same residential option. For example, life sharing (also referred to as shared care, foster care, and family model homes) can involve a family or a roommate and support may be provided by the family, the roommate or another individual outside the home. In addition, those individuals in a life sharing situation may live 1) in the home of a family or roommate, 2) in a jointly rented apartment or home, 3) in a home owned by the adult with the disability. This type of arrangement often has a minimum time commitment which also varies. This example highlights the variety that can exist within an accommodation option.

Much of the existing literature in this area centre on institutional and group home comparisons providing outcome data based on such a comparison. Given that British Columbia no longer operates institutions, such comparisons do not provide useful information. Instead, arrangements of interest are those beyond the institution and group home context. Research in this area is limited.

C.   Defining Key Terms

Literature in the area of residential options for adults with developmental disabilities comes from a variety of countries and communities around the world. Often times a term used to refer to a residential arrangement in one area of the world is different than the term used in another part of the world. Where

provided by the authors when referring to a type of arrangement, terms are defined within the body of the paper. This section provides general definitions of the various accommodations explored in this paper.

Semi-Independent Living Services

Semi-Independent Living Services provide support for people with DD who live for the most part independently and receive a limited amount of hours of services each week from paid staff. Support may be in the form of help with grocery shopping, paying bills or budgeting. Individuals receiving these services may live alone or with roommates in their own home or apartment (Hewitt & O'Nell, 1998).

Supported Living

A residential service model based on the provision of only those supports required by the individual who lives largely independently. Tailoring services to meet individual needs (Hewitt & O'Nell, 1998). Allen, Shea & Associates (2002) outline the characteristics of supported living as:

- Having support services separate from housing options (the person with DD has control over their home through home ownership, rent or lease). If an individual with DD's needs change, and an adjustment in service provision is in order, he or she does not have to move out of their living arrangement when changing their support services and service providers. This separates an individual's support needs from their housing needs;

- Service eligibility is not dependent on a person with DD's capacity to live independently;

- Services are person centered (individualized, flexible and centered around strength and ability, not disability);

- Personal choice and control is put in the hands of the individual, not the program; and,

- Natural supports (family, friends, community members, non-paid support) are encouraged.

Howe, Horner, and Newton (1998) summarize,

> Supported living is not facility-based. Rather than fitting people into existing residential facilities…that offer prepackaged services of a particular kind and level, supported living involves developing support that is matched to a person's specific needs and preferences and changing that support as the person's needs and preferences change. (p. 2).

Family Model Home/ Life Sharing/ Host Family/ Foster Care

"A home owned or rented by an individual or family in which they live and in which they provide care and support for one or more unrelated persons with ID/DD" (Bruininks, Byun, Coucouvanis, Lakin, Larson, and Prouty, 2005, p. 71).

<u>Family Home/ Family Support</u>

"A home owned or rented by a family member of a person with ID/DD in which the individual with ID/DD 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" (Bruininks et al., 2005, p.71).

<u>Cluster Housing</u>

Campus Type Living involves individuals with DD, living in close proximity to each other and forming a distinct community from the surrounding community. More specifically, Emerson (2004) defines cluster housing as "…accommodation located either as part of a campus development (three or more houses with an on-site day center) or in a cluster of houses for people with intellectual disabilities (e.g., a dead-end street with three or more houses for people with intellectual disabilities)" (p. 190). This type of living is the opposite of dispersed housing schemes.

Village Communities "…typically consist of a cluster of living units and other resources (e.g., day centers, shops, churches) that are physically segregated from the local community. They often aim to provide an intentional community of attachment in which people with mental retardation can be supported and provide support to their peers" (Emerson et al., 2000, p. 83).

To highlight the variation among definitions of the same terms, McConkey, Sowney, Milligan, and Barr (2004) use "cluster centres" to refer to "small institutions" (p. 420) providing 24 hour support to 12-25 residents. This type of cluster setting is quite different than the cluster settings described previously.

<u>Group Home</u>

A group home is one or more people with disabilities living in a typical home in the community and receiving full time services. These homes can range in size from 1 to 15 people and can be publicly or privately owned and operated (Hewitt & O'Nell, 1998). Some research studies included in this review defined group homes in slightly different ways. Where available, a more specific definition is given.

C. Deinstitutionalization and Trends in Residential Options: Canada, the US, the UK, and Australia

Throughout the world, trends in residential arrangements for adults with developmental disabilities demonstrate a decline in institutional living and an increase in group home living. Despite this trend,

institutional living is still a reality for many adults in parts of the world. However, this is not the case for adults in British Columbia as all institutions were closed in the mid 1990s. Many adults continue to live with parents or other family members. Interestingly, the percentage of individuals in supported living arrangements is starting to increase, particularly in B.C. and parts of the U.S. This section further outlines the trends in residential options for adults with developmental disabilities in Canada, the U.S., the U.K., and Australia.

Canada

In Canada, people with DD living in institutional settings of more than 100 people has declined significantly in the past twenty years (Braddock, Emerson, Felce & Stancliffe, 2001; Crawford, 1996; Pedlar, Hutchison, Arai, & Dunn, 2000; Taylor, 2001). Between 1981 and 1993, the number of people living in these settings dropped from over 10,000 to less than 8,000 (Taylor). During the same time period, the number of people living in small residential settings (i.e. group homes of 4-9 individuals) doubled (Taylor).

a.   *British Columbia*

Data specific to British Columbia was presented in the Adult Services Regional Quarterly Report prepared by Community Living British Columbia in March 2006. Results indicate that the greatest percentage of adults with a developmental disability live in the family home (37%) and "adult non-profit residence care" (30%). The other residential arrangements demonstrate the following breakdown: adult staffed proprietary residence (staffed group homes operated by the for-profit sector) (18%), adult semi-independent living – residential[3] (13%), microboard services – residential (2%), and intensive adult care services – residential[4] (1%) (Community Living British Columbia, 2006). In British Columbia, the majority of staffed proprietary and non-profit residences have less than 6 beds (87%). It is important to note that all institutions in British Columbia were closed in 1996.

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[3] Here semi-independent living refers to a type of living arrangement in which people typically have a greater degree of independence and capacity and live in their own apartment or in a home or apartment owned by a service provider. Those in semi-independent living do not require constant supervision or support.

[4] Intensive adult care services refers to intensive community based residential care and day services for adults with DD who have severe behaviour challenges that cannot be adequately responded to in a regular resource in the community. It also refers to the provision of community-based emergency care for adults with DD when current placements have broken down and alternative arrangements are being made.

As a point of comparison, Community Living departments in other provinces were contacted to inquire about residential options. This information was readily available in Saskatchewan.

b. Saskatchewan

According to the Community Living Division in Saskatchewan (M. Bordessa, personal communication August 22, 2006), there are three types of residential arrangements that exist within the province for adults with developmental disabilities; they include: group homes, group living arrangements[5], approved private service home[6], and supported living arrangements. As of March 2006, Saskatchewan had 130 group homes (approximately 768 spaces), 19 group living arrangements, and 270 approved private service homes. Data on supported living arrangements is not available as the supported living program is operated at a region level. There are five regions throughout Saskatchewan and it is estimated that there are at least 10 individuals in each region being supported by this program.

Cost data related to approved private service homes was available and exists in five levels of care categories in .5 increments. As of May 2006, the per person funds provided to the home operator per month are as follows:

Level of Care	Per Person Funds/Month
Level 1 *Requiring the least care*	$570.00
Level 1.5	$672.00
Level 2	$776.00
Level 2.5	$933.00
Level 3	$1052.00
Level 3.5	$1213.00
Level 4	$1373.00
Level 4.5	$1534.00
Level 5 *Requiring the most care*	$1695.00

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[5] Group living arrangement refers to a situation in which a small group of individuals with DD either choose to share a home or are recommended to share a home. These individuals live independently with life skills support as needed.
[6] "Approved private service home" is similar to private family care and family model homes in British Columbia.

These figures do not include the funds provided to the individual with a disability living in the home. Each client also receives funds for transportation, personal care, etc.

United States

Over the last quarter of a century, residential services for individuals with DD have changed substantially in the US (Braddock et al, 2001; Lakin, Prouty, Polister, & Coucouvanis, 2003). From 1977 to 2002, while the general population in the US increased by 33%, the total number of individuals receiving residential support increased by 60%. During this time, the number of people with DD living in state and non-state institutions decreased (72% and 41% decrease respectively) (Lakin et al., 2003). By 2002, this trend toward deinstitutionalization was present in every state in the US. In addition, community residential services increased throughout the country by 150%.

While the number of people with DD living in institutions (state and privately run) declined, non-state group homes consisting of 7-15 residents grew by 147% (Lakin et al., 2003). State-operated community setting residents consisting of 15 or fewer also increased dramatically by 977%, yet accounted for only 3% of all residential services. Over this 25-year period, the most dramatic increase of 1205% occurred in non-state residential settings accommodating six residents or less. Contrastingly, in 1977, the national average of residential service recipients that lived in settings of six or fewer people was only 8%. By 2002, that number had increased to two thirds of all residential service recipients (Lakin et al.). These statistics demonstrate that a decline in numbers of individuals with DD living in institutions was followed by an increase in the number of individuals living in group homes of varying sizes. In addition, increasing numbers of individuals were living in community placements with a smaller number of residents (i.e. under 6 people). According to Braddock et al. (2001), people with DD in the US were living in the following settings:

- Group homes (44.4%),
- Supported apartments (33.6%)
- Other residential settings (23.7%),
- Foster family care (17.2%),

- Natural parents (16.2%),

- Houseparent homes (9.2%), and

- Boarding homes (4.5%) (p. 116).

United Kingdom

Similar to those in Canada and the US, trends representing a shift away from institutional living were also displayed in the UK. Institutionalization in the UK was at its peak by the late 1960's when consideration for community service alternatives began to gain momentum (Felce & Emerson, 2005). By the 1980s, the governments of both Wales and England embraced deinstitutionalization policies that resulted in a marked decline in the institutional population of both countries in the following decades (Felce & Emerson).

Australia

Not surprisingly, trends in Australia like other parts in the world, favoured deinstitutionalization and the movement towards increased residential services within the community (Stancliffe, 2002). In 1999, the major types of accommodation support for individuals with DD were group homes (48.3%), institutions (30%) and outreach or drop in centers, such as support for semi-independent living (13.7%) (Stancliffe). However, Australia's housing situation, when compared to Canada's, appears to be behind in the transition to residential alternatives. Research has found that more individuals in Australia are housed in group homes and institutions than in Canada and less are housed in semi-independent settings (Braddock et al., 2001; Stancliffe). In British Columbia, individuals reside primarily in the family home or in group homes with a significant percentage living semi-independently (Community Living British Columbia, 2006).

D.   Community Living Services: The US, the UK and Australia

When exploring trends in residential options and supports for individuals with DD, it is useful to look at what is happening elsewhere in the world. Although exact international comparisons in this area are difficult for a number of reasons and therefore must be interpreted with caution, Stancliffe (2002) found that, compared to the United States and the United Kingdom, Australia allocated lower levels of government funded residential services for people with DD. Specifically, England had 22.3% higher levels of residential services and the US had 63.4% higher levels when compared to Australia (Stancliffe). Stancliffe asserted

that the marked differences in "residential provisions" are not a result of differences in the number of individuals with DD in these countries; instead, he stated, "…the lower availability of residential services in Australia appears to reveal a lower overall level of service to people with intellectual disability" (2002, p. 122). These findings are consistent with other international findings on residential provisions in the US, the UK and Australia (Braddock et al., 2001; Emerson & Hatton, 1998; Lakin, Prouty, Anderson, & Polister, 1997).

E.   Limitations of Group Homes

Group home living experienced an increase in popularity following deinstitutionalization. Despite the many other residential options in practice (e.g. supported living, life sharing), group homes continue to dominate as the standard model of care for people with DD in the US (Stancliffe, 2005; Stancliffe & Keane, 2000), Australia, and Canada (Braddock et al., 2001; Taylor, 2001). The limitations of this residential option however, are increasingly gaining attention from researchers and policy makers alike. For example, the 'one size fits all' concept for people with different levels of disability, diverse needs and unique personalities is being scrutinized and is no longer considered an acceptable standard of care. Although group homes are an improvement from institutional settings, there is increasing evidence that group homes may be too large and that for many individuals with DD, other service models, such as semi-independent living, may be more beneficial.

Group homes can be classified into small group homes and large group homes based on the numbers of people living within the home. Emerson and colleagues (2001) found small group home residents faired better than residents in large group homes. Features present in small group homes that contributed to these outcomes included having: larger social networks with more people who were not staff or family, social networks that were comprised of fewer individuals with DD, and higher numbers of unpaid social support. These residents were also less likely to be mistreated. The research also found greater levels of depersonalization in large group homes (Emerson et al.). Adults living in group homes and adults considering this option as an alternative to their present living option expressed concerns about problems

with co-residents and identified this as an undesirable feature of this type of accommodation (McConkey et al., 2004).

Even though small group homes have more positive outcomes than large group homes, multiple problems have been associated with such living arrangements regardless of their size (Emerson et al., 2001; Emerson, 1999; Howe et al., 1998; Stancliffe, 2005; Stancliffe & Keane, 2000):

- Inflexible schedules,

- High levels of staffing and control,

- Incompatibility and disputes among residents,

- Inability to adapt to residents' changing needs and preferences, and

- Low levels of personal choice and autonomy regarding group activities and decisions.

Not all individuals with DD need or want high levels of staffing. Some prefer to live alone and find incessant staff presence invasive. Specifically, results from an Australian study that compared group home residents to residents in semi-independent settings found that some group home residents "…may not need the high levels of staff support they receive, and that they may achieve similar or better outcomes, at lower cost, by living semi-independently" (Stancliffe & Keane, 2000, p. 302). For example, receiving staff assistance on a drop in basis for specific components of living, such as money management or health care, is preferable for some (Stancliffe, 2005). Thus, a greater variety of community living arrangements are necessary to accommodate the variable and distinctive needs and wishes of people with DD.

The ability to effectively accommodate these individuals will be increasingly important as the demand for community living arrangements in the next decade rises. Demographic factors that contribute to this demand include an increased prevalence of people with developmental disabilities from the baby boom generation who are currently cared for by elderly parents, increased life expectancy and lower mortality rates, and increased survival rates of young people with severe and complex DD (Emerson, 1999). Given the factors listed previously, there is reason to believe that residential services will see increasing demand from the following individuals:

1. Middle aged adults with low to moderate levels of disability,

2.   Older adults with DD, and

3.   Young people with severe and complicated disability (Emerson, 1999).

F.   Relationship between Staffing Levels, Costs and Quality Outcomes

Research exploring traditional and community residential settings found increased cost associated with the latter; however, the latter also demonstrated better quality outcomes. Of particular interest, and increased relevance, research examining semi-independent living and group home living highlighted lower cost outcomes attached to the former. In addition, the latter resulted in better quality outcomes in the domains of choice and community involvement. Similar research with adults with severe developmental disabilities highlighted comparable costs associated with supported living and institutional living. Cost and quality comparisons across studies is problematic for a number of reasons and should be interpreted with caution. This section further articulates the research in the area of residential arrangement outcomes.

The increasing demand for residential services will heighten the importance of moving toward more cost effective services that provide high quality living arrangements for people with disabilities. Repeated studies have shown that semi-independent living is a more cost effective alternative to group homes and also demonstrates more favourable outcomes (Emerson, et al., 2001; Emerson, 1999; Howe et al., 1998; Stancliffe, 2005; Stancliffe & Keane, 2000). Lower costs are not surprising considering semi-independent settings have part-time staff contrasted with the 24 hour paid staff in group homes (Stancliffe & Keane). In addition, Stancliffe and Lakin assert that because the essence of supported living is "assisting people to live out lifestyles of their own choice in homes of their own" (p. 3), it follows that more positive outcomes in the areas of choice and community participation would result in such living arrangements.

Felce and colleagues (1998) conducted an analysis on the relationship between staffing levels, costs and quality outcomes, for people with the most challenging behaviour and severest level of disability in traditional settings (i.e. hospitals and hostels), community houses (i.e. group homes) and family homes *(see Table 1)*. Over a three-month period, total accommodation and care costs per participant (including accommodation and onsite care, living expenses, day time activities and any other expenses such as medical and dental) for community houses cost on average £11,434 (approximately $23,258.53 CAD) more than

traditional services. A total average cost for community houses was £22,898 (approximately $46,575.10 CAD) compared to £11,464 (approximately $23,319.54 CAD) for traditional services. Accommodation and on-site care for each participant over the three months was £18,024 (approximately $36,663 CAD) for community houses and £9,891 (approximately $20,121.75 CAD) for traditional services. Living expenses were £436 (approx. $886.75 CAD) for community houses and £428 (approx. $870.48 CAD) for traditional services. Daytime activities cost £3913 (approx. $7,959.58 CAD) in community houses compared to £355 (approx. $722.12 CAD) in traditional services. All other services or expenses cost £524 (approx. $1.065.89 CAD) in community houses compared to £355 for traditional services.

Variation in costs among participants in different service models was great (Felce et al.). However, results indicated no relationship between costs and level of disability or between staffing ratios and severity of disability. "Higher staffing costs were related to more intensive staffing arrangements for individuals, but the relationship between resource input and need was weak" (Felce et al., p. 405). In general, community houses were found to be considerably more expensive than traditional settings but the former was determined preferable in many quality of life domains.

These findings are consistent with the wider literature on the weak relationship between costs and quality (Emerson et al., 2000). In the Emerson et al. (2000) study exploring the quality and costs of community-based residential supports and residential campuses for people with severe disabilities, findings indicated

> …significant between-model differences in the total costs of provision…However, analysis of the relationship between costs and quality across participants failed to reveal strong associations between costs and quality…Increased total costs were associated with poorer procedures for assessment and teaching, less block treatment, greater variety of community-based activities, and greater amounts of praise received by participants. (p. 276).

Interestingly, an earlier study conducted by Horner, Close, Fredericks, O'Neill, Albin, Sprague, et al. (1996) found that supported living options (i.e. a rented or owned home in the community in which the individual resides with 24 hour support) for individuals with severe developmental disabilities were comparable, and on average, better than institutional living. Horner et al. determined the average per person

cost for a supported living environment was $111,000 and $117,000 for institutional living. Cost data should be interpreted carefully as "Comparisons of costs in different locations require care to equate type and level of support provided and indexing of funds across years." (Horner et al., p. 234). Furthermore, both the Felce et al. (1998) study and the Horner et al. study had relatively small sample sizes (29 and 12 respectively) which pose challenges in quantitative research. (A*lso see Section G, page 18 on Residential Alternatives for People with Severe DD and Serious Challenging Behaviour*).

Table 1. Quality and Cost Outcomes: Comparisons Between Community Housing and Traditional Facilities

Based on findings from Felce et al. (1998)

Type of Residential Arrangement	Quality Outcomes	Cost Outcomes Based on a three month period:
Community Housing (i.e. group homes)	- More individualized treatment from staff, - Higher interaction with and assistance from staff, - Less social distance and less depersonalization, - Higher social and community integration, - More involvement in daytime activities, - Higher quality levels in evening and weekend activities, - Higher participation in domestic activities, - Higher reported feelings of autonomy, - Greater systemic working methods.	- Accommodation and on-site care: $36,663 CAD - Living expenses: $886.75 CAD - Day time activities: $7,959.58 CAD - Other expenses: $1,065.89 CAD - Total average cost: $46,575.53 CAD
Traditional Facilities (i.e. hospitals, hostels)	- Higher levels of challenging behaviour and disengagement, - Lower levels of autonomy, - Lower levels of social and community integration, - Less participation in daytime, evening, and weekend activities.	- Accommodation and on-site care: $20,121.75 CAD - Living expenses: $870.48 CAD - Day time activities: $722.12 CAD - Other expenses: $722.12 CAD - Total average cost: $23,319.54 CAD
Note: This comparison is based on a study of residential options for adults with severe and profound developmental disabilities.		

G.   Residential Alternatives: Severe DD and Serious Challenging Behaviour

Much of the research exploring residential options for adults with developmental disabilities focuses on mild disability. The limited body of research investigating such options for individual with severe developmental disabilities demonstrates success in transitioning these individuals from institutional settings to community settings. These settings ranged from regular houses in the community rented by the individual who received 24 hour support to small group living. Facilitating factors contributing to success included deliberate and flexible planning pre and post transition, variable staff rations to meet the individual's needs, and co-resident planning. Positive outcomes associated with the transition included increases in participation in meaningful activities, skill and competence acquisition, increased autonomy, and higher community participation. One area in which challenges remained was with regard to social interactions. This section further outlines the specific research in the areas of residential options for adults with severe developmental disabilities.

Service effectiveness is evaluated on the ability to promote quality of life for the individuals it serves. Housing that resembles traditional family homes, located in communities where individuals have a social network and well-organized and directed levels of support are seen as essential conditions for promoting quality of life (Emerson, Robertson, Gregory, Kessissoglou, Hatton, Hallam, Knapp, Jarbrink, Netten & Lineham, 2000; Felce et al., 1998; Lowe, Felce, Perry, Baxter & Jones, 1998; Mansell, McGill & Emerson, 2001). Many studies that have examined these conditions by exploring the costs and benefits of various options have focused primarily on individuals with mild to moderate disability. The results for this population have been favourable however, for those with more severe disabilities and challenging behaviour, deinstitutionalization and residential living has proven problematic (Felce et al., 1998; Mansell et al., 2001).

According to Mansell et al. (2001), individuals with challenging behaviour are more likely to be institutionalized, less likely to be offered residential services until the end of the deinstitutionalization process, and are more likely to be reinstitutionalized or sent to other institutions. Furthermore, they are at increased risk of abuse, live in restricted and bleak environments, receive very little staff contact, remain isolated from the community and personal support networks, and receive little help addressing challenging

behaviour (Felce et al., 1998; Mansell, et al., 2001). A few studies have addressed these concerns and have attempted to find better alternatives within the community for people with severe DD and severely challenging behaviour (Emerson et al., 2000; Felce et al.; Lowe et al., 1998; Mansell et al.).

A project described and evaluated by Horner et al. (1996) focused on moving 12 individuals with severe developmental disabilities and severe problem behaviours from institutions into supported living environments over a 4 year period. This project viewed supported living as a way in which "…people are supported as active participants in their communities regardless of the type and severity of their disability." (p. 209). These 12 individuals moved into regular houses in the community that they leased or rented living alone, with one roommate or with two roommates. All homes had 24 hour staff support with ratios ranging from 1:1 – 1:3 (in one case the ratio was 2:1).

Prior to the move into community, support plans for all individuals were developed. These plans outlined (a) where the person would live, (b) with whom the person would live, (c) the level and type of medical support required, (d) the staffing particulars, (e) a detailed plan for responses to problem behaviours, and (f) procedures for addressing other challenges (Horner et al., 1996, p. 217). Plans incorporated a variety of support strategies and were reassessed and revised on a regular basis. In addition, an organized process for implementing the support plans (e.g. developing routines for community activities, skills instruction, developing social contacts with unpaid individuals, developing systematic strategies for preventing and responding to problem behaviour) was in place.

Outcomes explored in this study included: health and safety, frequency and intensity of problem behaviours, physical and social inclusion, overall lifestyle, and cost effectiveness. Overall, Horner et al. (1996) found,

> …1) major problem behaviours decreased, 2) access to physically inclusive activities
> increased, 3) social networks and social activities improved, 4) health and safety were as
> good or better than under institutional support, and 5) these outcomes occurred at a cost
> that was comparable to the costs of providing institutional support. (p. 223).

Residing in supported living environments increased the amount of time spent engaged in activities from 40% in the institution to 80%. Furthermore, according to family/friends, these activities were the preferred activities of the individual. On a scale of 1-10 (10 = excellent), family/advocates and staff rated the overall

lifestyle of family members as 7.4 and 7.7 respectively. The area that continued to be a challenge was developing social supports and family/advocates rated this area as the lowest on the scale. Horner et al. asserted, "…ongoing assessment and support modification have led to lifestyles that involve regular contact with typical people, places, and events in the local communities." (p. 236).

In a more recent project undertaken by Mansell and colleagues (2001) created a Special Development Team[7] to help local services create individualized placements and develop the expertise to care for severely challenging (both behaviourally and developmentally) individuals within the community. The primary objective of this team was to ensure that these individuals had a good quality of life regardless of their level of challenging behaviour.

> The strategy also had the implicit objective of helping to demonstrate to local and national policy makers that well-planned community services provided the best option for all people with severe intellectual disabilities, including those presenting the most seriously disturbed behaviour (p. 247).

The project focused on individuals with the most exceptionally challenging behaviour and the severest level of disability who were currently institutionalized and had future care plans that involved re-institutionalization at another facility. The individual service plans created for these individuals following deinstitutionalization were expensive due to high levels of service. These individuals were placed in specialized staffed houses (defined as houses or apartments) with an average of 3 residents per placement (not all residents had a DD) and were supported by a team of staff. The costs of the specialized residential placements were much more expensive than ordinary staffed housing services but were comparable to specialized institutional placements (Mansell et al., 2001).

In order to measure quality of life, Mansell and colleagues (2001) conducted direct observations of service users and how they spent their time. Mansell and colleagues asserted that such research approaches

> …avoids inadvertently confounding measures of process and outcome; where evaluations have used measures of, for example, individual program goals achieved it may be that the result owes more to staff activity (in this case, in setting achievable goals) than to real differences in service user experience (p. 258).

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[7] The Special Development Team was created "…to enable local services to develop the expertise to maintain individuals with serious challenging behaviour in the community." (Mansell et al., 2001, p. 247).

In addition, Mansell et al. felt user activity patterns provided a sound basis for comparison with other research results because they have been widely studied in British DD services research. Furthermore, the researchers asserted that "…if low levels of engagement in meaningful activity are found this reflects a genuine problem whatever other measures may indicate" (Mansell et al., p. 258).

The study found that all participants, once transferred from institutions to staffed houses, showed a statistically significant increase in their overall participation in meaningful leisure, personal, and practical activities which led to more participation in activities and less sedentary behaviour (Mansell et al., 2001). Participants' increased engagement in meaningful activities also led to an increase in skills and competence. Staff contact increased in the form of practical help (i.e. assistance and support for participants in everyday activities) which is important for people with severe developmental disabilities. However, social interaction in the residential facilities did not increase and was still very low. Overall, Mansell and colleagues emphasized that, "Increased engagement in meaningful activity means that people are living fuller, richer lives despite the severity of their intellectual disability and the continued presence of behaviour problems" (p. 271).

Mansell et al. (2001) also examined changes in problem behaviour. Challenging behaviour either improved or stayed the same for 7 out of 13 participants, while 6 of the 13 participants demonstrated increasing minor challenging behaviour, major challenging behaviour or both. The effects of these individuals' challenging behaviour on co-tenants were not directly studied and only informal observations could be made. The Special Development Team attempted to avoid placing multiple people with challenging behaviour together and found that threats and attacks on co-tenants were low; however, there were undoubtedly times when co-tenants' living environments were unstable and frightening. On the positive side, co-tenants may have benefited from outside professional involvement, structured programming, and elevated staffing levels (Mansell et al.).

Mansell and colleagues (2001) suggest interpreting the results of this study in terms of added value. Staffed houses in this study had double the staff in institutions but were providing 3.4 times the staff contact and 4.5 times the assistance to the individuals served. Overall, Mansell et al. found that it was possible to

establish residential alternatives in place of hospitals for people with severe disability and extremely challenging behaviour. Community-based placements offered a much richer social and physical environment, and involvement in meaningful activities and level of competence increased as a result. "The evidence of this project suggests that even specialist institutional provision, including hospital-based housing, provides a very poor quality of life for clients, despite the resources which have been invested in it" (p. 284).

In a similar study, Felce and colleagues (1998) compared the costs and outcomes of different service models for individuals with severe DD and extremely challenging behaviour. These service models included family homes, hospitals, hostels and community housing (i.e. group homes). Participants were residing in these settings at the time of the study. In family homes, participants lived with parents and siblings and received little professional support. Hospitals and hostels were combined to form a distinct traditional service group characterized by a

> …large living unit and facility size, atypical architectural design, relative isolation from the community, a greater level of buildings adaptations, low staff:resident ratios, a relatively high percentage of qualified staff, and a relative absence of systematic approaches to goal planning and structured activity (Felce et al., p. 392).

Community housing was characterized by "…less emphasis on qualified staff but a greater emphasis on systematic working methods" (p. 392).

Data was obtained through direct observation with participants and through interviews with primary carers. The cost analysis was limited to the residential services and did not include family homes (Felce et al., 1998). For the purposes of this paper, the study's findings on residential services will be the focus. Results indicated that community living settings had the following features in comparison to traditional facilities:

Quality of life

- Residents received more individual treatment from staff, less block treatment, less social distance and less depersonalization than residents living in a traditional setting. These findings were not related to the skill level of staff or staff:client ratios.
- Residents were much more likely to be involved in daytime activities.

- The highest quality of evening and weekend activities.

- Residents received much higher interaction and assistance from staff than those in traditional care.

- Greater systemic working methods than traditional facilities.

- Participation in domestic activities was higher in community setting residents.

- Autonomy was higher in the community settings.

- Social and community integration was higher in community settings both in frequency and number of events.

- Residents engaged in social, domestic, personal and leisure activities almost twice as often.

- Contrastingly, traditional settings demonstrated higher levels of challenging behaviour and disengagement.

H.   Residential Alternatives to Group Homes: Research Findings

As outlined in *Section B: Defining Key Terms*, there are many residential alternatives to group homes. Some alternatives, such as supported living, exhibit many positive features such as personally tailored supports, increased choice, and living in a way that is consistent with individual preferences. However, it is also important to note that individuals in this type of accommodation may experience some social isolation and community separation due to a lack of planned activities. Life sharing is an alternative receiving limited research attention and exists on a continuum. Individuals living according to this option may live with family or a roommate in their own home or the home of the individual with whom they live. Quality and cost outcomes associated with this option are difficult to determine as each arrangement has distinct defining characteristics.

Home ownership has been presented as a potentially desirable option which can enable stability and enhance choice. Various types of home ownership are discussed in this section. Cluster housing and co-housing are similar housing options with individuals living in a separate community. In cluster housing, an individual may live in a building or a neighbourhood with other individuals with developmental disabilities and support is available within the community. Research has not demonstrated positive outcomes associated with cluster housing. Co-housing is an intentional community comprised of a group of individuals (with or

without disabilities) who wish to live in an informally supportive neighbourhood. The various alternatives mentioned above are explored in further detail within this section.

<u>Cluster Housing: Residential Campuses and Village Communities</u>

As mentioned earlier, campus type living arrangements are defined as

> …accommodation located either as part of a campus development (three or more houses with an on-site day center) or in a cluster of houses for people with intellectual disabilities (e.g., a dead-end street with three or more houses for people with intellectual disabilities) (Emerson, 2004, p. 190).

In this arrangement, individuals with DD live in close proximity to each other and form a distinct community from the surrounding community. In comparing cluster housing to dispersed housing schemes (houses located throughout the community) in the UK, Emerson (2004) found that individuals living in cluster housing were more likely to:

- Live in larger settings,

- Receive support from fewer staff,

- Experience greater changes and irregularity in living arrangements,

- Be exposed to restrictive management practices (i.e. seclusion, sedation),

- Lead more sedentary lives,

- Be underweight, and

- Experience leisure, social, and friendship activities that were more restrictive in nature.

In terms of costs, " …the adjusted comprehensive costs of provision in dispersed housing schemes were 15% higher than in residential campuses and 20% higher than in village communities" (Emerson et al., 2000, p. 81).

These findings are consistent with other research studies in the UK that compared the quality and costs of cluster housing to dispersed housing and found that cluster housing was associated with a poorer quality of care and a poorer quality of life (Emerson, Robertson, Gregory, Hatton, Kessissoglou, Halam, et al., 2000; Emerson, Robertson, Gregory, Kessissoglou, Hatton & Hallam et al., 2000).

a. United States

In the United States, the trend towards greater integration with the larger community and smaller residential settings has demonstrated a number of positive outcomes. Howe et al. (1998) compared traditional residential services (i.e. group homes) with supported living in the state of Oregon. According to Emerson et al. (2001), this study provided the first published formal evaluation of supported living by matching 20 supported living residents with 20 participants receiving traditional support.

Results indicated that individuals in supported living arrangements experienced social and community based activities to a greater extent than individuals receiving traditional services even though costs were similar. No statistically significant difference in public support costs between supported living services and group home services was found. They also found supported living residents were significantly more likely to:

- Have fewer housemates with disabilities (0.63 housemates vs. 5.88 housemates for group home/traditional service participants),

- Have more staff support and supervision,

- Be owners of the residence or have their names on the rental agreement,

- Have housemates (or no housemates) consistent with their preferences,

- Have had their personal preferences taken into consideration during the initial development of support,

- Be the decision makers about their daily affairs, and

- Receive services with a written policy stating they were not required to meet any "entry criteria" with regard to adaptive behaviour (or lack of problem behaviour) to be served (Howe et al., 1998, p. 6).

In reviewing the study conducted by Howe et al. (1998), Emerson and colleagues (2001) identified two design limitations.

First, matching participants on level of mental retardation (mild or moderate) may have failed to ensure the equivalence of samples on adaptive behaviour, a participant characteristic that has repeatedly been shown to be associated with the outcomes of residential supports. Second, the comparison confounded the effects of model of provision (supported living vs. traditional) with facility size (p. 402).

An understanding of these limitations is important for future research in this area that attempts to match participant groups for the purposes of comparison.

b. United Kingdom

When considering the costs and benefits of different types of residential alternatives for people with DD, it is important to demonstrate that resources are allocated on the basis of scientific evidence, need, and high quality outcome at a reasonable cost (Emerson, 1999). In the United Kingdom, Emerson and colleagues (2001) conducted research with 152 large group home residents (i.e. 4-6 co-residents), 55 small group home residents (i.e. 1-3 co-residents), and 63 supported living residents. The results demonstrated similar service costs for each type of provision once participant characteristics were taken into account. Quality outcomes indicated that supported living residents, when compared to group home residents, had greater choice and took part in more community based activities. Unfavourable outcomes association with the former accommodation provision included fewer planned activities, higher rates of home vandalism, and greater risk of mistreatment.

When considering the staffing features of supported living compared to small group homes, supported living arrangements demonstrated higher staffing ratios, higher ratios of care staff, and more effective internal processes for distributing support staff based on resident need (Emerson et al., 2001). In addition,

…a greater proportion of supported living residences showed program characteristics (housing and support provided by different agencies, residents holding legal tenancies) that are claimed to be either defining of, or desirable of such residences (Emerson et al., p. 407).

Residents in supported living arrangements however, were less likely than small group home residents to have a designated key worker, an "Individualized Habilitation Plan" (p. 407), and consistent and effective access to assessment and teaching supports.

Research exploring the perspectives of adults with developmental disabilities found that adults living in supported living arrangements strongly valued the independence that this arrangement afforded (McConkey et al., 2004). In addition, participants spoke of the freedom and privacy associated with supported living. Some concerns about this residential option included "the possible lack of support" (p. 122) from staff, potential boredom due to living alone, and issues of safety. Of the 180 adults living in a variety of residential arrangements who participated in this study, most indicated supported living as a favourable alternative to their current arrangement.

KeyRing and Neighbourhood Networks, England and Scotland

In England and Scotland there are "living support networks" which support individuals with developmental disabilities to live in their own homes in their own communities (Neighbourhood Networks, d/u). KeyRing (www.keyring.org) is the support service in England and has been operating for 12 years. "KeyRing's 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. You can walk easily from one property to another. Nine flats or houses belong to people with learning disabilities (developmental disabilities). They have assured tenancies like anyone else. The tenth is occupied by KeyRing's Community Living Worker (CLW) who works part time on a flexible basis. This enables KeyRing to build layers of support around the network members." (KeyRing Living Support Networks, d/u). The CLW also works with the network members to create a mutual support network in which each member shares his/her skills with other members. Further connections to the community are fostered through the CLW.

The KeyRing Network Manager is another key player in this support service. The responsibilities of this role include providing support to network members in difficult areas such as benefits (KeyRing Living Support Networks, d/u). An after hours line is also a part of the service to support members when the CLS is unavailable. "As network members experience the robust strengths of this network of support, they can become less dependent on workers and more confident in using their own resources and those of their neighbours and the wider community. In this way KeyRing achieves truly empowering outcomes and at a cost to commissioners which is affordable even in times of financial constraint." (KeyRing Living Support

Networks).   The Neighbourhood Network (www.neighbourhoodnetworks.org) in Scotland is based on KeyRing and operates in much the same way as described above.

To respond to the needs of individuals with developmental disabilities living in rural areas, KeyRing has begun a new project called Neighbour Networks. This project offers the same support as the KeyRing network except the distance between each member may be greater however, still within walking distance (KeyRing Living Support Networks, d/u). The CLW will encourage and facilitate gatherings of the members to prevent feelings of isolation. Another component of the Neighbour Network will respond to the interests of those individuals who are thinking about independent living. These individuals will meet up with network members to see what living on one's own is like.

Outcomes

KeyRing undergoes an external evaluation every three years. The most recent findings demonstrated that KeyRing performs well overall and outperforms many other organizations (KeyRing Living Support Networks, d/u). More specifically, in the areas of community building, self-reliance, involving KeyRing members, and having a voice KeyRing positive outcomes are displayed. Network members are becoming involved in their communities at faster rates than in previous years. "At least half of the relationships enjoyed by KeyRing's members were seen to be a direct result of KeyRing support." (KeyRing Living Support Networks). KeyRing members reported feeling proud of what they can do individually and as part of a team.

c. Australia

Stancliffe and Keane (2000) conducted a matched comparison of outcomes and costs associated with group homes and semi-independent living for people with disabilities in Australia. Group homes were defined as housing between 3-7 residents with full time day support. Staff were present at all times when residents were home and awake. Night support was optional but could be provided either in the form of sleepovers or awake shift support. Semi-independent living was defined as 1-4 residents living in a household with part-time support by paid providers. Staff provided daytime support on a regular basis. Residents, when at home, were without staff support for at least 28 waking hours a week and no sleepovers or overnight staff was

provided. Individuals living in both settings were matched based on adaptive and challenging behaviour scores as well as the incidence of other disabilities. Matching ensured participants had equivalent support needs, which were low to moderate in this study.

In line with the above definitions, Stancliffe and Keane (2000) found that semi-independent participants lived in significantly smaller households, with an average of 2.3 residents per household compared to an average of 4.22 residents per household in group homes. In addition, group home participants had more staffing than semi-independent participants, averaging 160.41 weekly paid staffing hours compared to 19.80 hours respectively. This represents a difference of 140.61 weekly paid staffing hours which is 300% more paid staff support than semi-independent participants.

In terms of service costs, per consumer staff support hours and annual (non-capital) costs on accommodation support services were far greater for group home residents than for semi-independent settings. The mean annual total residential cost for semi-independent living was $14,602 compared to $64,105 for group homes.

Information about general quality of life and life satisfaction outcomes was gathered from residents with DD and their direct support staff. Residents were interviewed about levels of social dissatisfaction, aloneness, safety and quality of life. Support staff provided information on more factual lifestyle issues such as

> …personal care, domestic management, health care, money management, social network,
> use of mainstream community services, community participation, participation in
> domestic tasks, stability of place of residence, living companion turnover, and natural
> support (Stancliffe & Keane, 2000, p. 288).

Results demonstrated that individuals living in semi-independent housing attained more favourable results on 5 of 29 outcomes as follows: greater empowerment, less social dissatisfaction, more frequent and independent use of community facilities, and increased participation in domestic tasks. Group home residents did not obtain significantly better scores on any measured outcomes but similar scores were found on 24 outcomes. "In short, most outcomes were similar, but where differences were evident they consistently favoured semi-independent participants" (Stancliffe & Keane, 2000, p. 298). Stancliffe and Keane attributed these findings to differences in living and support arrangements between group homes and

semi-independent settings. Stancliffe and Keane concluded that group homes were less cost effective than semi-independent services. In addition, semi-independent residents had similar or better outcomes even though they received less staff support at less cost.

Choice in Living, State Government of Victoria, Australia

One example of semi-independent living options in Australia is the Choice in Living residential program. Choice in Living is a new program in Victoria, Australia receiving Accommodation Innovation funding from Victoria's Department of Human Services (M. Buntine, personal communication, September 4, 2006). According to the Disability Services, Department of Human Services' website,

> CIL offers local people of the Alexandra district, 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 have already established relationships and community ties, after their families are no longer able to support them in the family home. (Accessed September 1, 2006, http://hnb.dhs.vic.gov.au/ds/disabilitysite.nsf/sectionthree/accomm_innovation_grants?open#cil).

More specifically, Megan Buntine, Project Office for CIL, explained that the funding received was to help five people with developmental disabilities achieve their goals in life (M. Buntine, personal communication, September 4, 2006). These life goals centered on moving out and having a place of their own. Currently, CIL, in collaboration with Supported Housing Limited (an affordable housing association), is in the process of buying land, refurbishing existing houses, and building new houses. This plan was initiated based on the needs of five people receiving day program support from a service agency in Australia. Some of the individuals will require in home support and have received funding for such supports from Victoria's Department of Human Services. CIL is supported by three staff positions – project management, project officer, and an ongoing network support worker – the funding for these positions comes from the Accommodation Innovation funding.

Life Sharing

Life sharing, family model homes, roommates, host families and adult foster care are some of the terms used to describe "a home owned or rented by an individual or family in which they live and in which they provide care and support for one or more unrelated persons with ID/DD" (Bruininks et al., 2005, p. 71).

For the purposes of this paper, life sharing will be the term used to describe this type of accommodation. The term life sharing more adequately defines the guiding philosophy of this type of living arrangement; a planful and deliberate coming together of individuals committed to sharing their lives, or a portion of their lives, with one another. Life sharing is an innovative term gaining popularity in British Columbia. It is replacing terms used in the past such as family model homes because these terms confuse the living situation with that of an individual's biological family. People with DD already have a family and this living situation is not meant to replace them. The term family model home also does not adequately describe situations where individuals with DD choose to life share with a roommate. Although this type of residential arrangement for adults with DD has existed for years, there has not been much research conducted on life sharing. Thus, existing literature in this area is sparse.

Based on an American study that examined the statistics and trends of residential service provision for individuals with DD, Bruininks et al. (2005) found that the number of people engaged in life sharing services is gradually increasing. In addition, almost all of these individuals are living with 6 or fewer residents with a DD; "…of the 39,857 persons with ID/DD reported in [life sharing] settings, all but 19 lived in settings with six or fewer residents (p. 71).

One program based out of Wyoming examined the outcomes of placing individuals with DD in life sharing settings (Walling, Potts, Fortune, Cobb, and Fortune, 2000). Thirteen adults with DD that previously resided in institutions or placements with a regional service provider (i.e. group homes) were sent to live with care providers for 7 to 11 months. The individuals' level of DD ranged from mild to profound and ages varied from 23 years to 65 years. The Inventory for Client and Agency Planning (ICAP) was used to track individual progress or regression. The ICAP "…is a comprehensive, 123-item standardized instrument to assess the adaptive functioning, problem behaviour, functional characteristics and service needs of individuals with developmental disabilities" (Walling et al., p. 10). Informal methods of data collection, such as incident reports, medication changes, and nursing notes were also used.

Walling and colleagues (2000) found a positive change for all thirteen individuals placed in life sharing settings. There was an improvement in all ICAP results. Maladaptive scores, adaptive scores, and service scores showed a change for the better.

> The increase of an entire ICAP service level would indicate the positive effect [life sharing has] on a person with developmental disabilities compared to the same individuals while they lived in an institution or at the beginning of their placement with a regional service provider[8] (p. 11).

The informal data collection methods also found an improvement in the thirteen individuals. Inappropriate behaviour significantly decreased in eight individuals. All thirteen individuals maintained or improved their health status. These results should be interpreted with caution however, due to the small sample size and limited amount of alternative living options for comparison. Comparing life sharing to early placement with a regional service provider does not provide a good indication of the long term effects of these living situations either.

In a study exploring the views of 180 adults with developmental disabilities living in various residential settings, shared care (living with another unrelated family) was explored (McConkey et al., 2004). The findings were as follows,

> …the majority of participants commented that they would prefer to live with another family member rather than move in with a family to whom they were unrelated. They saw this as "betraying" their family by choosing someone else to live with. (p. 122).

Another concern noted by participants was what would happen to them if the family (care provider) no longer wanted the adult to live with them. Participants wondered "What would happen then?" (p. 122). When asked if anyone wished to live in this arrangement, none of the participants responded affirmatively.

Due to the limited amount of research in the area of life sharing, a more extensive examination of programs offering life sharing services will be discussed. *(Please refer to Section I, page 40 for a more detailed discussion of Life Sharing in Canada.)*

Co-Housing

Co-housing first emerged in Denmark more than twenty-five years ago and was introduced to North America in 1988. Today, co-housing accounts for 10% of all new housing developments in Denmark. Co-

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[8] Regional service provider in this context refers to a group home.

housing incorporates strata title home ownership "…in an environment where all owners want to be in relationship with their neighbours and live in a more supportive and cooperative environment" (Planned Lifetime Advocacy Network, 2006, p. 4). In this multi-family development, individuals own their own homes and have joint ownership of common areas.

> Groups typically are born when an individual or small group of friends begins to spread the word about co-housing with the goal of creating a co-housing community. Occasionally, someone already owns a site they feel will be appropriate (The CoHousing Company, 2003, www.cohousingco.com).

These homes are situated around a communal house with shared amenities such as a kitchen, dinning room, laundry, guest rooms, home office support, workshops, and arts and crafts. All privately owned homes are self-sufficient with complete kitchens. Dinners in the common house can occur frequently or occasionally, depending on residents' preferences (Canadian Cohousing Network, 2004).

Home owners are involved in the planning, design, management and maintenance of the community. These heterogeneous communities generally range from 10-35 households. Co-housing residents consist of individuals young and old, singles, families, couples and people with disabilities. These communities exhibit pedestrian friendly and environmentally sensitive design (Canadian Cohousing Network, 2004). A co-housing development is designed by the owners and varies depending on their needs, wants and resources. These communities are democratic and do not support any ideology other than the aspiration to live in a more social and environmentally sustainable community.

Over 40 co-housing communities have been created in the US and Canada with hundreds more in various stages of development. There are currently eight completed communities across Canada. Five are located in British Columbia, two are located in Alberta and one is located in Ontario. In British Columbia, the five co-housing communities can be found in Burnaby, Nelson, the Sunshine Coast, North Vancouver and Langley (Canadian Cohousing Network, 2004). Additional co-housing communities are currently being developed in British Columbia, Manitoba, Nova Scotia, Ontario, and Saskatchewan. British Columbia and Ontario are seeing the largest increase of co-housing developments. British Columbia has six new co-housing developments underway in Bowen Island, North Delta, Vancouver, Courtenay, Nanaimo, and the

Upper Fraser Valley. Ontario has five new communities being created in Ottawa, Toronto, Orillia, and Caledon (Canadian Cohousing Network).

Cohousing networks in Canada have included children and adults with developmental disabilities (V. MacIntyre, personal communication, August 22, 2006). There are no communities at this time that include only individuals with developmental disabilities or only families with children with developmental disabilities. It is important to note that cohousing communities are centred on being a part of a neighbourhood in which all people are known to one another. They do not provide the type of formal support that might be necessary for some individuals with developmental disabilities to live independently within the community (V. MacIntyre, personal communication, August 22, 2006).

Co-Operative Housing

According to BC Housing (www.bchousing.org), co-operative housing is a type of subsidized housing that is available to "…frail seniors, people at risk of homelessness, people with disabilities, and low-income families, including women and children fleeing abuse." This option includes the following features: (a) co-ops are jointly owned and managed by the residents, (b) residents participate in decision-making, (c) residents share in the operation of the co-op, and (d) residents select new co-op members (BC Housing, 2003).

Table 3. Differences Between Co-ops and Co-housing

Co-ops	Co-housing
• Rented	• Owned
• Subsidized	• Not subsidized
• Federally funded	• Privately funded
• Fixed rent	

Home Ownership

The following information on home ownership originates from resource documents provided by Planned Lifetime Advocacy Network (2006). Further information can be obtained through the PLAN website (www.planinstitute.ca) and by attending their workshops on housing options.

According to PLAN, 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 has control over the type of home they purchase and where it's located. There is stability and security with ownership. A home is a good investment that can accumulate in value with time. With home ownership an individual has greater influence and control over roommate selection and length of stay. Home ownership doesn't affect income assistance and there are additional grants available.

There are many things to consider when planning for home ownership. Vulnerability, disability benefits, taxes, financing, competency, support services, and monitoring are considerations for potential home owners. First, individuals with DD may be vulnerable to exploitation if the home is in their name. Predators may try to persuade the individual to relinquish control over the home. Second, a home is tax exempt if the individual is the owner and resident. BC Disability Benefits offers $325 a month for housing expenses. This funding must be spent on housing costs such as mortgage payments, strata fees, telephone, maintenance, etc. It may be beneficial to ensure that the individual with DD is set up to receive housing benefits.

Third, planning to minimize taxes must be considered. An individual's primary residence is not subject to capital gains tax. A person on disability benefits that owns a home and is the principle resident is also eligible for the home owners grant as well as an additional grant. If part of the home is going to be used as a rental property, income generated from the rental will affect income tax. If the home is in the individual's name, rental income will be deducted from disability benefits.

Fourth, how the home is going to be financed and by whom needs to be considered. Fifth, "the person with a disability may not be legally competent to buy or sell real estate or to make a will, etc. This can complicate the purchase, sale and management of a residence" (Planned Lifetime Advocacy Network, 2006, p. 3). Sixth, the level and type of support services needed for an individual with DD to live in their own home should be given substantial thought. Finally, planning for monitoring processes to ensure services are being delivered and that the individual is managing well is important. When purchasing home insurance,

the type of home insurance should be tailored around potential situations that could arise with having caregivers providing service in the home.

Types of Ownership:

    a.   Full ownership in the name of the individual with DD

This option has benefits coupled with a number of important considerations.

    BENEFITS:

- Individual has control over the purchase and sale of the home.
- No capital gains tax applies for principal residence.
- Disability Benefits are not affected.
- Eligible for home owners grant and supplementary grant.

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    CONSIDERATIONS:

- If the individual decides to sell the home, the money from the home will go to him/her.
- The sale of the home can affect disability benefits.
- The individual is in a vulnerable position to be taken advantage of.
- The person needs to be considered competent by lawyers.
- The individual may have to make legal decisions, such as creating a will, signing a mortgage and other financial considerations.

    b.   Joint tenancy (ownership) between a parent and a person with DD

With this type of shared ownership, when the parent passes away, ownership is passed directly to the individual with DD and is not part of the will. A particular risk association with this option is that the individual could be at risk of exposure to creditors. Other benefits and considerations are similar to those outlined in option a.

    c.   Part ownership (e.g. 5% / 95%) tenants in common

In this type of ownership, a parent purchases the home and retains ownership over a certain percentage of the home (e.g. 5%), while the individual with DD owns the rest (e.g. 95%). The proportions of ownership however, can be tailored to fit each individuals needs. In this example, the parent's will must indicate what

happens to their share of the home upon their death. A family member, the individual with DD, or a trust can be identified as the beneficiary.

BENEFITS:

- The parent maintains some control over: the sale of the property and who resides in the home.
- The individual with DD is less likely to be taken advantage of with this type of arrangement.
- Parents have the option of making the person with DD the beneficiary of the remaining ownership of the house upon the parents' death.
- The parents can also will their percentage of ownership to a trust set up for the person with DD upon their death.
- As long as the person with DD is living in the home, capital gains taxes are payable on only the parent's share.

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CONSIDERATIONS:

- Agreement by both owners is necessary to sell the house.
- Parents can will their percentage (e.g. 5%) to another family member and that family member will retain the same control that the parents had. This arrangement can be problematic if the person with DD wants to move.

d. Home owned by a trust

This option has a number of benefits and fewer risks. "The trust can be an Inter Vivos Trust set up while the parent is alive or a testamentary trust set up in the parent's will. It must be a discretionary trust as the asset value will likely exceed the statutory limit of $100,000" (Planned Lifetime Advocacy Network, 2006, p. 7). This will make certain it is not considered a personal asset to the individual with DD.

BENEFITS:

- This option protects the individual with DD from being taken advantage.
- Competence is not an issue.
- The trustee can manage the household finances (hydro, cable etc.). Rent could be charged to the individual to cover the expenses.
- The trustee can manage the rental details when/if roommates are involved. In this case, the income generated from the rental will not affect disability benefits.
- If the home is sold, disability benefits will not be affected because the trust will receive the capital gain.

- "The disposition of the home asset on the sale or on the death of the person rests with the person setting up the trust. Assuming the person with a disability lives in the home, capital gains taxes are payable on only the 5% parent's share" (p. 8).

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CONSIDERATIONS:

- A reliable, trustworthy, identifiable trustee must be designated.
- Not eligible for the homeowners grant.
- May not be eligible for the principle residence capital gains exemption.
- "Capital gains taxes are payable every 21 years whether the house is sold or not. This could force the sale of the home" (p. 8).

e. The parent helps the person with DD purchase a home by providing financial assistance and then sets up a mortgage against the property

BENEFITS:

- The individual with a DD has the benefits of home ownership.
- The assets are protected.
- "The mortgage can be at no or low interest, due if the home is sold, or on demand, or on the death of the person with a disability" (p. 9).
- The mortgage is the parents' asset and can be willed to the individual with DD, a trust, or a sibling.

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CONSIDERATIONS:

- "The capital gain will belong to the person, if it is greater than any interest accumulated by the mortgage, and the person should have a will to dispose of" (p. 9).

f. Home placed in a trust with a life interest

This option is similar to the previous option but with further advantages. "After placing the home in a trust, the trustees grant the person with a disability a 'life interest' for their exclusive benefit and enjoyment of the home. Upon their death, the residence is transferred back to the trust and distributed in accordance with the terms of the trust. If a person with a disability acquires a life interest, if will qualify as a principle residence and capital gains will not be payable on the death of the individual" (p. 9).

Table 2. Overall Quality Cost Comparison

Type of Residential Arrangement	Characteristics	Quality Outcomes		Cost Outcomes
		Favourable	Unfavourable	
Group Homes	Several individuals living in a community home receiving full time support; vary in size.	• 24-hour care/supervision available to those individuals who require such care • Organized access to formal supports in the disability community	• Often too large • Inflexible schedules • High levels of staffing/control • Incompatibility among residents • Inability to adapt to changing needs • Low levels of choice & autonomy	• Greater annual accommodation support services costs compared to semi-independent living or similar costs • Example of mean annual total residential cost: $64,105 *(based on the findings from one study)* • Paid staff support 300% greater compared to semi-independent living
Cluster Housing	<u>Campus:</u> housing is part of a campus development or a cluster of houses. <u>Village:</u> cluster of living units segregated from the local community.	• Likely to have an assigned key worker • Likely to be supported by staff with formal qualifications _____ *Emerson (2004) reported, "There appear from our data to be few potential benefits of living in cluster housing." (p. 195).	• Larger settings • Fewer staff providing support • Greater changes and irregularity • Restrictive management practices • Limited activities, sedentary lifestyle • More restrictive leisure, social, & friendship activities • Poorer quality of care • Poorer quality of life	No data available (Currently, study in this area is sparse.)
Family Home/Support	Home owned or rented by family or individual in which individual receives paid care and support.	• Consistency of care • Care providers are known to the family/individual which leads to increased community participation • Increased opportunities for choice related to living space	• Fewer resources available to families • Planned activities may be minimal or non-existent which could result in social isolation	No data available (Currently in BC it is against the law for the government to give family members financial support to care for a family member.)

Family Model Homes	Individual resides with a non-relative family receiving support and care from this family.	• Individual remains in a family home in the community	• Commitments are often time limited • Some family model homes may have more than one person with a DD supported in the home	(See p. 10 for Saskatchewan's breakdown of payment to "approved private service homes")
Roommate Living	Individuals share an apartment with an adult without a disability; ideally, roommates are matched based on lifestyle and interests.	• Individuals more likely to have choice and input regarding home and roommate	• Commitments are often time limited • Vulnerable to disruption	Varies depending on arrangement
Supported Living	Support services are separate from housing options. This option is not facility based rather, support is matched to the specific and changing needs of the individual.	• Increased flexibility & adaptability • Greater choice • Increased community participation • Increased social activities • Higher staffing ratios • Higher ratios of care staff	• Fewer planned activities • Higher rates of home vandalism • Greater risk of mistreatment/exploitation • Less likely to have designated key worker (compared to small group homes) • Less likely to have an Individualized Habilitation Plan	• More cost effective than group homes or at least similar • Can be provided without increasing avg./person costs
Semi-independent Living	Individuals live mostly independently with limited hours of support by paid staff.	• Increased choice in lifestyle • Greater empowerment • Less social dissatisfaction • Increased use of community facilities • Often living in own home • Increased community participation • Typically associated with individuals requiring low levels of support • Smaller households	• Planned activities may be minimal or non-existent which could result in social isolation	• More cost effective than group homes or at least similar • Can be provided without increasing avg./person costs • Example of mean annual total residential cost: $14,602

Outcomes in this table are summarized results from the following studies: Caldwell & Heller, 2003; Emerson, 1999; Emerson, 2004; Emerson et al., 2000; Emerson et al., 2001; Felce et al., 1998; Howe et al., 1998; Parish, Pomeranz-Essley, & Braddock, 2003; Stancliffe, 2005; Stancliffe & Keane, 2000; Stancliffe & Lakin, 2004.

I.   Residential Alternatives and Canada

This section of the paper reviews various residential programs/supports throughout Canada. It is not intended to be a comprehensive review; a more detailed program analysis will be provided in a future document – particular attention will be paid to the section focusing on residential options in British Columbia. Alternatives in parts of Canada include supported apartments, life sharing/alternative family support, direct family support, independent living, subsidized housing, and microboards. These options are programs operated by various agencies/organizations throughout Canada. Further detail is provided in the following pages. Please note, this section is meant to highlight some options that exist for which information was readily available.

<u>Maritimes</u>

In 2002-03, Nova Scotia initiated the Community Supports for Adults (CSA) Renewal Project to review the Community Supports for Adults program. The purpose of the project was to discover ways of improving support services for people with disabilities (Nova Scotia Community Services, 2005). Consultations were held with service users, advocacy groups, service providers, Department of Community Services staff and other government departments in Nova Scotia to gather opinions and suggestions regarding improved services (Nova Scotia Community Services). Out of the project, three new programs were initiated: Supported Apartments, Alternate Family Support and Direct Family Support.

   a.   Supported Apartments

According to Nova Scotia Community Services, Nova Scotians were highly supportive of expanding the Supported Apartment program. The Supported Apartments option refers to semi-independent living for individuals with low level needs. In this model, independence is respected and encouraged. "This option is viewed as one of the least-intrusive programs of support for individuals…who are semi-independent and require minimum level of support and supervision" (Nova Scotia Community Services, 2005, p. 12). The CSA renewal project also received feedback in support of a model of independent living transition. A formal planning process is developed with the client to assist in support and preparation for their transition to independent living (Nova Scotia Community Services).

b.   *Life Sharing (Alternate Family Support)*

The CSA Renewal Project also received strong encouragement for "…an enhanced Alternate Family Support model, a program that provides care for individuals in a non-relative private home in the community." (Nova Scotia Community Services, 2005, p. 13). Another program in existence, the parent Resources for Information Development and Education (PRIDE – a child welfare foster care training program) was identified as a model to follow.

> According to the jurisdictional research, this model of support for persons with disabilities is well developed, highly used and an important service in the overall continuum in a number of provinces. These jurisdictions place strong reliance on this model, which enables individuals to live in the community in a family setting (Nova Scotia Community Services, p. 13).

Important areas to consider and plan for were cautious screening, training, monitoring, and compatibility.

This program is similar to Life Sharing Programs currently offered in other provinces. Nova Scotia currently has a limited number of Alternate Support Programs but considers this type of program one of the preferred service options. Implementation and expansion for this program started in 2005 (Nova Scotia Community Services, 2005).

c.   **Direct Family Support**

Direct Family Support refers to financial assistance provided to families that are caring for a family member with DD currently living at home. This program has been offered since early 2005. Direct Family Support helps the entire family by providing financial assistance as an alternative to residential placement for approved disability support costs (Nova Scotia Community Services, 2005). The goals of the support are: (1) to enable individuals to live at home, (2) to maximize family supports and community participation, (3) to prevent and/or delay the need for an out of home placement, and (4) to establish a smooth and seamless transition between children's and adult's supports and services (Nova Scotia Community Services, Department of Community Services, 2006, p. 2).

> The DFSA [Direct Family Support for Adults] component recognizes that families supporting an adult with a disability have different responsibilities and unmet support needs. Therefore, the Individual and their family may be entitled to receive funding for assessed unmet needs which may include shelter, food, clothing, prescriptions, transportation, a comforts (personal use) allowance, and other approved items included in the SPD policy and procedures. (Nova Scotia Community Services, Department of Community Services, 2006, p. 3).

Eligibility criteria for the DFSA component include the following: the individual must (i) be between the ages of 19 and 65, (ii) be a resident of Nova Scotia, (iii) have a primary residence with a family member or guardian, (iv) have a medical diagnosis of intellectual disability and/or long term mental illness and/or physical disability, (v) have unmet needs as determined through the assessment process ((Nova Scotia Community Services, Department of Community Services, 2006, p. 12). Ongoing eligibility is determined through annual review. Once families have received funding through the program for respite, the families locate and choose respite workers. If they are unable to do so, the Care Coordinator of the DFS program shall provide information about locating respite workers.

Ontario

Ontario offers a number of accredited Community Living support services for people with disabilities.

a. Independent Living

Avenue II (d/u) based out of Thunder Bay, Ontario has an independent living program called N.E.I.G.H.B.O.U.R.S. that stands for Normalized Entry Into Generic Housing Based on Unique Required Supports. They provide individualized support, based on clients' personal wants and needs, to make it possible for individuals with DD to live independently in their own homes. Some individuals choose to live alone while others prefer living with another person with a disability. The amount of support varies depending on the individual and their personal support plan. Support ranges from a few hours a week to around the clock care. When overnight support is required, Avenue II provides a non-disabled, live-in roommate, who is on duty from 10pm-8am daily and lives as part of the household (Avenue II, d/u).

British Columbia

a. Life Sharing

In 2001, the Burnaby Association for Community Inclusion (BACI) introduced the Life Sharing Network. BACI currently receives funding from Community Living British Columbia (CLBC) to assist with the costs of life sharing for 29 individuals with DD. Within the Life Sharing Network, three support options are available (Burnaby Association for Community Inclusion, 2004):

1. The individual with DD either occupies a bedroom and shares communal space with a roommate or family, or lives in a self contained suite within the family home.

2. The individual with DD lives in an apartment next to a family. The family is responsible for assisting the individual with DD to develop independent living skills.

3. Respite: "the goal of respite is to enable primary caregivers to obtain several days of rest and renewal (a weekend or holiday) while BACI provides a safe, enjoyable and meaningful experience for the individual. Respite can be provided in the individuals own home, in a family home within [the] Family Care Network, or in a staffed home" (p. 1).

BACI receives block funding from CLBC for a designated number of individuals with DD to provide living or respite support by placing them with a non-related individual, family, or couple within the person's community (Burnaby Association for Community Inclusion, 2004). Matching people in terms of location helps ensure current support networks will be maintained. Life sharing candidates are also matched in terms of personality characteristics to help foster the relationship and promote a positive experience for both parties. Caregivers receive anywhere from $2200 to $8000 a month (depending on the level of disability) to share their lives with people with DD. Caregivers that receive smaller amounts of funding are supporting individuals that are high functioning, relatively independent, have low medical needs, and low levels of support. Those receiving higher amounts of funding are supporting individuals that are lower functioning, have higher health care costs, and require full time support (personal correspondence, BACI, 2006).

Caregivers that participate in life sharing are not employees of BACI. They are independent contractors and have more flexible regulations than employees of BACI. Before participating in life sharing, a one-year commitment is made between parties but if something arises and the contract needs to be terminated, 30 days notice is expected. There are no penalties for terminating early. If harm is suspected at any point, the agreement can be terminated immediately and the individual with DD can be removed from the household or the caregiver/s are asked to leave. After a year, the contract can be terminated or renewed for another year, depending on both parties' wishes (personal correspondence, BACI, 2006). Currently there is a waitlist of caregivers wanting to life share with individuals with DD. Whenever possible, BACI tries to

put the rental lease under the name of the person with DD. This ensures that the individual with DD will not have to leave their home if the living situation does not work out. The caregiver will move out instead. This is not the case however, when caregivers already own a home and the individual with DD moves in with them.

b.   Assisted Living: Subsidized Housing

BC Housing "…is a provincial crown agency that provides affordable housing options for British Columbians in greatest need." (www.bchousing.org).   More specifically, BC Housing offers subsidized housing to people with disabilities that qualify for the Independent Living BC (ILBC) Program. To qualify for funding, individuals with disabilities must be eligible to receive a disability pension, or unable to work because of their disability and be able to live independently. This program offers an alternative to home care and residential care for people who need some assistance but don't want or require 24-hour care. To qualify, potential candidates must be referred by their local health authority.   Individuals who qualify pay 70% of their after-tax income to live in assisted living homes. Assisted living services include, accommodation, personal care services, such as assistance with self care needs and hospitality services (e.g. meals), laundry, housekeeping, recreational activities and 24-hour response (BC Housing, retrieved May, 2006).   The program is delivered in partnership with non-profit and private housing providers, regional health authorities and the federal government through Canada Mortgage and Housing Corporation. As of October 2005, 3,300 assisted living apartments were built with 200 more to come. Rent supplements are funded exclusively through the provincial government (BC Housing, retrieved May, 2006).

Subsidized Housing includes all types of housing where people with low to moderate incomes receive some form of subsidy or rent assistance by the provincial government. This includes co-operative housing, public and non-profit, as well as rent supplements for people that own their own home (BC Housing, retrieved May, 2006). Financial support for subsidized housing is generally allocated based on:

> Rent-geared-to-income…for low-to-moderate income households. Tenants pay rent based on the gross income of the household rather than paying the market rate. Affordable rent is defined as costing no more than 30% of a household's total gross monthly income, subject to a minimum rent that tenants will be asked to pay based on the number of persons living in the home. Rent-geared-to-income units include all public

housing stock and many developments managed by non-profit and co-operative housing providers (BC Housing, p. 1).

<u>Types of Subsidized Housing (BC Housing, retrieved May, 2006):</u>

a. *Public Housing* (and group homes): BC housing is responsible for 7,800 public housing units and over 300 group homes.

b. *Non-Profit Housing*: Non-profit societies offer subsidized housing and are the landlords under the Residential Tenancy Act.

c. *Co-operative Housing* (Co-ops): "Housing co-operatives are jointly owned and managed by residents, who become co-operative members. Members participate in decision-making, share the responsibilities of running the co-operative, and select new members" (p.1)

c.   Vela Microboard Association

According to the purpose statement of the Vela Microboard Association (www.microboard.org), this non-profit organization is

> …dedicated to exploring, facilitating, 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 has two primary roles, they are: (1) to facilitate the development of Microboards and provision of on going support to Microboards for people with disabilities throughout British Columbia and (2) to provide affordable housing for people with disabilities. According to CLBC's Adult Services Regional Quarterly Report (2006), 81 adults with developmental disabilities in British Columbia use their microboard to make residential arrangements.

Vela has affiliates in other parts of the world. Between the period of 1998 and 2004, the Vela Microboard Association of BC has worked with individuals and families in Northern Ireland (Vela Microboards NI Ltd., www.velamicroboardsni.org.uk) to create an environment that would support the development of microboards. Microboards also exist in southwest Virginia through an organization called "Community Opportunities" (www.communityopportunities.org). According to Community Opportunities,

> Members of a microboard have a personal relationship with that person. They act as "bridge builders" to the community, and ensure that the person has opportunities to

participate in their community in as many ways as possible. Microboard members also help develop the resources and support the person needs to reach his or her dreams. They make sure the services the person receives are individualized to meet that person's needs. Another important job is to find ways for the person to contribute to community. (Microboards - www.communityopportunities.org/page4.html).

J.   Conclusion

Recent trends emphasizing inclusion and self-determination have resulted in a shift in residential attributes reflecting choice, community living, and active participation. With this shift came residential alternatives to group homes such as life sharing and semi-independent living. Research has begun to explore these alternatives in terms of cost and quality outcomes and has identified many favourable quality outcomes associated with residential alternatives. Some of these outcomes included: increased choice, greater empowerment, and individualized support. Unfavourable outcomes associated with these residential options have also been identified in recent research; the theme of such outcomes centred on the potential for social isolation based on a lower level of planned activities. However, such awareness is useful as planning can be specifically targeted to minimize or remove unfavourable quality outcomes.

As of March 2006, most adults in BC with a developmental disability resided in the family home or in non-profit residence care. Similar findings exist for the United States with most adults residing in a group home but less living in the family home. Interestingly, Braddock et al. (2001) found a large percentage of adults in the US living in supported apartments. The percentage of adults in BC living in such an arrangement was considerably smaller. According to Stancliffe (2002), most adults in Australia lived in group home with a large percentage of adults living in institutions. Institutional living is no longer an option in BC; all institutions were closed in 1996.

Group homes became the living situation for many adults following the closure of institutions. Although there are some positive attributes associated with group home living (e.g. 24 hour support, community-based living), recent research has pointed to many unfavourable characteristics. For example, large group homes have demonstrated greater levels of depersonalization with residents having smaller social networks. Group homes in general may be characterized by inflexible schedules, high levels of staffing, inability to adapt to changing needs of residents, and low levels of self-determination and autonomy. When

looking at cost data, group homes, compared to semi-independent living, demonstrated less cost effective outcomes.

For adults with severe and complicated developmental disabilities, housing options are often limited with many adults living in institutional environments. Such environments lead to unfavourable outcomes centering on isolation. Some effort to create desirable living options for *all* people with varying levels of disability has been undertaken (see Felce et al., 1998, Horner et al., 1996, & Mansell et al., 2001). Research in this area has demonstrated success in implementing residential arrangements classified as "supported living" (Horner et al.). Horner et al. stated, "…results…indicate that it is possible for people with histories of very extreme problem behaviours to become active members of their local communities…[leading] lifestyles that involve regular contact with typical people, places, and events in the local communities." (p. 236). Further attention in this area is needed.

There are several alternatives to group homes that have been explored in recent literature each with benefits and limitations. *Cluster housing* in the form of residential campuses is an alternative that involves the formation of a distinct community in which individuals with developmental disabilities are living in close propinquity. Research in the UK found cluster housing to demonstrate poorer quality of care and poorer quality of life. Contrastingly, s*upported living* has resulted in positive outcomes such as: greater involvement in social and community based activities, greater opportunities for home ownership and decision-making with regard to roommates and daily affairs, and higher staff ratios with a more effective process for distributing and providing support. Some research in the US and the UK has not found a statistically significant difference in cost when comparing supported living with group homes. However, research in Australia found significant differences in costs when comparing group homes and semi-independent living[9].

Life sharing is when an individual with a developmental disability lives with another person or family (other than the biological family) for a committed period of time. In some cases, the individual may

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[9] Comparisons across studies and across countries/regions are problematic for a number of reasons. One main challenge centers on the proliferation of terms used to refer to various residential options. This is further complicated by the lack of term definitions. Thus, when "supported living" is referenced in an article, it does not necessarily mean the same as "supported living" referenced in another article.

own the home and choose a life sharing "roommate" to move in. This can allow for more stability for the individual with a disability. However, in situations where individuals are placed with another family in the family home, vulnerability due to familial changes is possible. *Co-housing* is an intentional community created by a group of individuals and families who wish to live in a more supportive and cooperative environment. Because this type of arrangement is organized by those who wish to live in the community, the creation and function of the community is flexible to the needs and wants of those coming together in the community. *Co-operative housing* is similar to cohousing except that co-ops involve rentals rather than ownership and are federally funded and subsidized. Finally, *home ownership* on the part of the person with a disability can result in increased stability, a sense of pride and status, and increased control in roommate selection. There is a risk or exploitation association with this arrangement. In addition, individuals would likely also need some support (depending on the needs of the individual) to live independently in this way.

Currently in BC is it illegal to directly pay families to care for an adult family member with a developmental disability except in exceptional circumstances, though families and individuals are eligible for a range of other supports. Many people with a developmental disability in BC live in the family home which means that families are responsible for many of the costs related to this living arrangement. Interestingly, in Nova Scotia, families can receive funds for having their family member at home. *Direct Family Support* helps the entire family by providing financial assistance as an alternative to residential placement for approved disability support costs (Nova Scotia Community Services, 2005). This program should be further explored as an option for BC families.

Residential services will be in increasing demand for middle aged adults (baby boom generation), older adults (increased life expectancy), and young adults with severe disability (increased survival rates); thus, this area of service/support requires serious exploration and the availability of a multitude of options to meet the needs of this individualized population. An awareness and understanding of the favourable and unfavourable quality of life and cost outcomes enables for planning that serves to capitalize on the favourable and minimize, or create additional supports to respond to the favourable. In general, research has

found that residential options that resemble family homes and are located in communities where individual have a social network as well as well-organized and directed levels of support promote quality of life.

Finally, a note on the limitations and gaps in the current research is needed. As noted, caution must be exercised in cross jurisdictional comparisons both in terms of the research and the programme models. With regards to the research it is fair to say that while reasonable data is available on cost and outcome comparisons of institutional versus community options, research on cross community options is limited. A further caution needs to be made when comparing community options, a given type of service or model will vary greatly depending on the operation of the programme and needs of the people residing in them. Few studies have reliably been able to capture this complexity. Similarly for programme examples, it cannot be assumed that because one example of a given model shows positive outcomes that all examples will follow suit, particularly where there is a great deal of variation in administration and operation. For examples, a small life sharing options with good quality controls may differ greatly than a simple family placement with few planning or support features.

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