Encouraging Aging Parents of an Adult Child with a Developmental Disability to Plan for the Future

by

Janine Marie Twist

B.A., Simon Fraser University, 2013
B.Sc., University of Saskatchewan, 1984

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Approval

Name: Janine Marie Twist
Degree: Master of Public Policy
Title: Encouraging Aging Parents of an Adult Child with a Developmental Disability to Plan for the Future

Examining Committee:

Chair: Doug McArthur
Director, School of Public Policy, SFU

Judith Sixsmith
Senior Supervisor
Professor

Joshua Gordon
Supervisor
Assistant Professor

Maureen Maloney
Internal Examiner
Professor

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Abstract

A future plan is key to directing and continuing supports for a person with a developmental disability. Despite its importance, many aging parents of an adult with a developmental disability do not have a future plan ready for the time when they will be unable to provide supports. This study explores why some parents in British Columbia do not have a future plan and proposes government actions to encourage future planning. Semi-structured interviews with parents, non-profit and government employees reveal barriers that hinder future planning in the areas of financial, housing, and service processes. Case studies of different jurisdictions examine the current supports for people with disabilities and present possible solutions to facilitate future planning. Four policy options mitigating the barriers are evaluated: an information campaign, increasing housing choices, utilizing a navigator role, and increasing respite. All options are superior to the status quo.

**Keywords:** future plan; developmental disability; aging parents; support network; housing choice; barriers to planning
To parents of children with a disability.
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I would like to thank my husband who has supported me in pursuing further education. His support over the last six months has carried me. I am looking forward to the years ahead.
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<tr>
<td>ADD</td>
<td>Adult with a developmental disability</td>
</tr>
<tr>
<td>BC</td>
<td>British Columbia</td>
</tr>
<tr>
<td>CLBC</td>
<td>Community Living British Columbia</td>
</tr>
<tr>
<td>DSP</td>
<td>Disability Support Pension (Australia)</td>
</tr>
<tr>
<td>DTC</td>
<td>Disability Tax Credit (Canada)</td>
</tr>
<tr>
<td>DMS-IV-TR</td>
<td>Diagnostic and Statistical Manual of Mental Disorders, (Fourth Edition)</td>
</tr>
</tbody>
</table>
| EPCIT   | Elderly Parent Carer Innovation Trial in Queensland, AUS.
| GSA     | Guide to Support Allocation |
| HAFI    | Home Adaptations for Independence |
| HCBS    | Home and Community-Based Services (USA) |
| PLAN    | Planned Lifetime Advocacy Network |
| PWD     | Person with Disability Pension (BC) |
| RDSP    | Registered Disability Savings Plan |
| RFSL    | Request for Services List |
| SAFER   | Shelter Aid for Elderly Renters |
| SDSI    | Ministry of Social Development and Social Innovation |
| SSI     | Supplemental Security Income (USA) |
| STADD   | Services to Adults with Developmental Disabilities, BC |
| UNCRPD  | United Nations Convention on the Rights of Persons with Disabilities |
| WLS     | Wisconsin Longitudinal Study |
### Glossary

<table>
<thead>
<tr>
<th>Term</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adult with a developmental disability (ADD)</td>
<td>A person over the age of 19 years who meets the DSM-IV-TR criteria for mental retardation.</td>
</tr>
<tr>
<td>Disability Tax Credit (DTC)</td>
<td>A designation granted by the Canada Revenue Agency to persons who are severely disabled. Required for RDSP eligibility.</td>
</tr>
<tr>
<td>Guide to Support Allocation (GSA)</td>
<td>A tool used by the CLBC to determine the overall support level needed by the disabled adult. The adult is assessed in ten areas and scored on a level of 1 to 5 where 1 indicates no support is required and 5 indicates the highest level of support is needed. The ten scores are averaged to produce determine the support level. (CLBC, 2014)</td>
</tr>
<tr>
<td>Request for Services List (RFSL)</td>
<td>A list of current service requests from disabled individuals or their families. (CLBC, 2014)</td>
</tr>
<tr>
<td>Parental Caregivers</td>
<td>A mother or a father or guardian who provides regular and long-term care for their son or daughter with a disability.</td>
</tr>
<tr>
<td>Register Disability Savings Plan (RDSP)</td>
<td>A saving account for qualified people with a disability. The federal government of Canada provides grants and matching amount to contributions. The person with a disability can withdraw funds to pay for living expenses.</td>
</tr>
<tr>
<td>Persons with Disability pension (PWD)</td>
<td>A monthly BC payment to qualified people with a disability. The purpose is to off-set the low employment rate for this group</td>
</tr>
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</table>
Executive Summary

Aging parents co-residing with their adult child with a developmental disability face the substantial challenge of finding suitable housing and services for their child at the time when they can no longer provide these supports. Increased life expectancy for people with developmental disabilities has led to many adults with a disability outliving their parent caregivers (Weeks, Nilsson, Bryanton, & Kozma, 2009). At the same time, these individuals depend on others to maintain their quality of life and, commonly, parents provide most of the supports (Salvatori, Tremblay, & Joyce, 2003).

As parents age and become elderly, the need for planning for the future becomes more urgent. The caregiving that the parents previously supplied needs to be replaced by support from other family members or by the government. The provincial government, through Community Living BC (CLBC), manages and funds accommodation arrangements and services for living support. However, CLBC has acknowledged their resources are strained by the increasing caseloads resulting from adults urgently requiring government support when aging parents cease their caregiving. CLBC and non-profits organizations scramble to provide supports when the parent’s caregiving stops. Despite the consequences, many aging parents do not plan for the future (Jokinen, Janicki, Hogan, & Force, 2012; Heller & Caldwell, 2006) resulting in a crisis management situation for the government agency and less than satisfactory outcomes for the adult with a developmental disability.

The objective of this study is to address the policy issue that the lack of future planning by many aging parents co-residing with an ADD in the province of BC results in crisis or urgent situations that stress government and family resources. Studies on future planning have revealed barriers facing parental caregivers such as lack of information, distrust of government, waitlists, challenges in housing and residential services, parental beliefs, low family savings, the state of health of the parents, and whether there are siblings of the adult child. However, there are no studies of future planning in British Columbia. In order to inform policy options aimed at remedying the problem in BC, two research questions were proposed: 1) what do stakeholders perceives as influences on planning for the future by parent who take care of their adult
child with a developmental disability? and 2) what can the provincial government do to encourage parents to have future plans?

Two methodologies were employed to answer these questions. The first was semi-structured interview with parents, government employees and non-profit organization employees. Future planning is a sensitive topic and to reduce the risk of emotional harm, parents who were interviewed met two conditions: referral by a non-profit organization and they had undertaken future planning. Five parents were interviewed. The government viewpoint was provided through semi-structured interviews with four individuals who were either working for CLBC or employed through the Ministry of Social Development and Social Innovation. Seven employees of non-profit organizations provided the service provider input for the research questions. The second methodology employed to answer the research questions was case study analysis. The case studies of BC, Queensland and Washington State informed this study of the supports for parents and for adults with a developmental disability, and provided insights into ways to encourage future planning.

Thematic analysis of the findings from the two methodologies revealed a model for future planning and nine significant barriers to future planning facing aging parental caregivers. The model illustrates that future planning is an ongoing temporal process that has three interconnected elements or categories: financial and legal structures; housing; and services and supports. Barriers were identified that hinder aging parents in BC from planning. A general barrier that obstructs future planning is the lack of knowledge on how to start planning. The eight additional barriers that were identified specific to one of the elements of future planning. In the financial/legal element the two barriers are: lack of understanding of representation and estate planning; and the lack of family financial resources. Housing also has two barriers: the lack of accommodation and the lack of housing choice. The service and support category had the largest number of barriers which indicate a high level of concern held by the parents, non-profit organizations and government regarding future caregiving. The barriers to future planning in this category are: the difficulty of maintaining a support network; parental worries about future caregiving; parental exhaustion from caregiving; and the lack of understanding of the role of government in providing supports.

In response to the barriers, four policy options were proposed. Each of these options is currently in use or in a trial phase as indicated in the case studies and the
options are: an information campaign, implementation of housing grants, establishing a navigator role, and tying increased respite to future planning activities. Four criteria were used to evaluate the four options: the equality of opportunity for all families with an adult with a developmental disability; the capacity of the option to serve all families and avoid waitlists; the effectiveness of the option in encouraging future planning; and whether the option would be deemed acceptable to the stakeholders.

I recommend the province of British Columbia implement an information campaign and create government employee positions based on the navigator role in the Services to Adults with a Developmental Disability (STADD) program for individuals over the age of 55 years. The information campaign encourages parents to plan for the future and gives parents the information to start planning and how to seek more assistance. Providing navigators to assist aging parents throughout the province would address four barriers: parents do not know how to start future planning, parents cannot afford to pay for support network management, parents are worried about future caregiving, and managing support networks to look after caregiving is difficult for parents. Information campaigns have been used by CLBC and the navigator role is currently being tested in a selected area of BC.

Further research is needed to examine future planning by parents in BC. Statistics on persons with a developmental disability should be kept in order to inform policies. Future considerations that may affect future planning policies are the implementation of individualized funding and the impact of new technologies on caregiving.
Chapter 1.

Introduction

Two positive developments have occurred in the past fifty years in the lives of people with developmental disabilities. First, individuals with developmental disabilities are not routinely institutionalized but are, instead, included in community life (Gross, Wallace, Blue-Banning, Summers, & Turnbull, 2012; Yoong & Koritsas, 2012). Secondly, individuals are living longer because of medical advances (Jokinen, Janicki, Hogan, & Force, 2012; Salvatori, Tremblay, & Joyce, 2003). As a result of these developments, many adults with a developmental disability (ADD) are outliving their aging parents (Weeks, Nilsson, Bryanton, & Kozma, 2009; Burke, Taylor, Urbano, & Hodapp, 2012). However, this presents a dilemma because ADDs require supports and caregiving necessary to maintain their quality of life and, in extreme cases, the ability to live (Salvatori et al., 2003). Parents provide the majority, if not all, of the supports.

Parental caregivers are aware that they will need help in providing care or that their child may need to change residences but many parents do not have a known, workable future plan for the time when they can no longer provide caregiving (Jokinen et al., 2012; Heller & Caldwell, 2006; Taggart, Truesdale-Kennedy, Ryan, & McConkey, 2012). Many parents provide shelter in the form of the family home, and within these homes parents provide homemaking, socialization, meals, and transportation, as well as providing supports for emotional and health-related well-being. It is estimated that only 50% of parental caregivers of an ADD have a future plan for residency (Joffres, 2002; Heller & Kramer, 2009).

Increasing the number of parents with a future plan is critical for securing future supports necessary for the well-being of ADDs. A future plan outlines the resources that the family can provide and the resources that must come from outside the family. The
process of planning is started by the family, which may include input from the ADD. Planning for future supports takes time to put into place (Taggart et al., 2012) and this is especially critical where resources are required from non-family sources. If transitions are planned, there is the higher likelihood of a positive outcome (Jokinen et al., 2012).

Governments also play a role in providing supports to ADDs. Since the majority of parents and ADDs have limited financial resources (Seltzer, Floyd, Song, Greenberg, & Hong, 2011), they struggle to pay privately for supports and often rely on the government funding these supports (Ouellette-Kuntz, et al., 2014; Jokinen et al., 2012). The British Columbia government, through Community Living British Columbia (CLBC), is committed to improving the lives of ADDs by funding supports such as housing options, respite care, day programs, and services for daily living. The level of government support varies between individuals, and the supports either supplement the caregiving provided by the parents or replace some aspect of the parental caregiving. CLBC is a crown agency and must meet the demand for supports without exceeding their fixed budget. Urgent, unplanned requests for services strain CLBC’s funding (Queenswood Consulting, 2008).

Compounding the stress on government resources is the uncertainty surrounding the actual numbers of ADDs who are living at home with aging parents (Salvatori et al., 2003). In BC for the year 2013, approximately 58% (representing over 9,100) of ADDs registered with CLBC were not living in government-managed housing and were presumed to be living in the family home (CLBC, 2014). In addition to this figure is the undetermined number of ADDs who are not registered with CLBC.

The challenge of accommodating aging families is recognized in the 2014 CLBC annual report: “The capacity to cope with adults living at home diminishes as family caregivers grow older. The result is an increasing number of adults requiring support some of whom have never had prior contact with CLBC.” (CLBC, 2014, p. 10). Despite the acknowledgement of elderly carers of ADDs, there is a lack of government policies and the support is provided on a reactive or crisis-basis (Ryan, Taggart, Truesdale-Kennedy, & Slevin, 2012). Without knowing the scope of the future demand on government services, the resources and the funding are not fully budgeted.
Many aging parents are cognizant of the need for future planning but view it is a difficult, stressful, and uncertain undertaking (Taggart et al., 2012). When plans are not in place for financial, housing, and caregiving resources, crisis situations occur when parental caregiving abruptly stops, usually due to illness or death. The lack of planning by the parents and the lack of resources provided by the government often results in hastily-made decisions that are not satisfactory for the government, the family and, most concerning, the ADD (Joffres, 2002; Taggart et al., 2012; Heller & Kramer, 2009). Conversely, planning for the future is associated with better outcomes (Jokinen et al., 2012) and research is required to understand why parents do not plan.

The policy problem addressed in this paper is the lack of future planning by many aging parents co-residing with an ADD in the province of BC results in crisis or urgent situations that stress government and family resources. Both parents and governments recognize the importance of planning necessary supports to ADDs to maintain their quality of life in the future, yet, barriers or influences appear to overwhelm the process of future planning.

The study is presented in several sections. Section 2 gives the background by defining the population of the study, listing the current government stance towards the population, and examining the literature on future planning. Section 3 presents the methodology used to explore the research questions is presented. Section 4 presents the overall findings from the case studies, semi-structure interviews, and literature review. Proposed policies options that can remedy the barriers that parents face and encourage future planning are derived from the findings and presented in Section 5. Criteria and measures to provide an evaluation framework for the policy options are presented in section 6. In section 7, a policy analysis is undertaken using the criteria measures. In section 8, the recommended option to increase the number of parents with a future plan is presented along with concluding remarks and other considerations.
Chapter 2.

Background

2.1. Defining the population

This section defines the populations directly affected by future planning: adults with a developmental disability and their aging parents. The prevalence rate, standard definition and other characteristics of people with a developmental disability are presented. Defining aging parents is taken from other studies on future planning. Defining the target population of aging parents co-residing with ADDs is proposed.

2.1.1. Definition of adults with a developmental disability

The standard prevalence rate for individuals with a developmental disability established by the World Health Organization is 1.05% of the general population (CLBC, 2014). Applying the World Health Organization rate to the population of British Columbia\(^1\), there are approximately 45,000 individuals with a developmental disability in the province and this number would include those under the age of 19 years.

The majority of those 45,000 individuals need support to maintain their quality of life and, in some cases where other mental or health conditions exist, the ADD requires support to live. “As a result of their underlying conditions and associated comorbidities, many persons with DD require lifelong family and organizational support for a broad range of health and social service issues, including (but not limited to) housing, employment, education, recreation, and transportation.” (Shooshtari, Naghipur, & Zhang, 2012) The discourse below expands on the reality of the disability.

\(^1\) According to 2011 National Household Survey, BC’s population is approximately 4.3 million
**Definition of developmental disability**

Developmental disability for the purpose of this paper refers to the definition of cognitive impairment used by the provincial crown agency, Community Living BC, in determining the eligible population for disability services. CLBC follows the DMS-IV-TR criteria to define developmental disability (CLBC, 2010). Developmental disability, also known as mental retardation, is defined in the America Psychiatric Association’s manual, the *Diagnostic and Statistical Manual of Mental Disorders*, as a neurodevelopmental disorder. Three diagnostic criteria must be met for an individual to be diagnosed with mental retardation: 1) sub-average intellectual functioning indicated by an IQ of 70 or lower; 2) the individual requires support in two or more areas such as communication, self-care, home living, social participation, community living, self-direction, functional academic skills, work, leisure, health and safety; and 3) the onset of the condition occurs before the age of 18 years (American Psychiatric Association, 2000). Common causes of developmental disability are Down syndrome, Fragile X Syndrome, Prader-Willi Syndrome, and diseases and conditions of the central nervous system (National Advisory Council on Aging, 2004) but 30-40% have no known cause (American Psychiatric Association, 2000).

**Co-morbidity and aging**

Individuals with a developmental disability have a higher probability of comorbidity with medical conditions or mental disorders, and these conditions affect the caregiving required by the individual (Heller, Miller, & Factor, 1997; Salvatori et al., 2003). Autism spectrum disorder, depression, hyperactivity, and anxiety are some of the mental health issues that occurred 3 to 4 times higher in individuals with intellectual disabilities in comparison to the non-developmentally disabled population (American Psychiatric Association, 2000). An Ontario study of 154 families in 2012 illustrates this comorbidity: 49% of adults with a developmental disability presented with medical conditions, 40% had a behavioural problem or mental health issue, and 25% had mobility issues (Ouellette-Kuntz, et al., 2014).

Although this study is examining aging parents and future planning, any examination also needs to factor in the aging of the ADDs. As the ADD ages, it is more
likely they will develop other health conditions making it more difficult for aging parents to look after them at home. Like the non-disabled population, diseases and challenges associated with aging vary by individual, however some aging conditions can occur sooner than in the non-disabled population (Salvatori et al., 2003). Dementia and hearing impairment can occur at an earlier age in individuals with Down syndrome (National Advisory Council on Aging, 2004; Jokinen et al., 2012). Prader-Willi Syndrome has an increased risk of diabetes and cardiovascular disorders. Diagnosing these and other diseases and conditions associated with aging is difficult because of communication challenges (National Advisory Council on Aging, 2004). Parents, especially those who provide a significant amount of care for their child, worry about their child’s and their own aging (Salvatori et al., 2003).

2.1.2. Definition of aging families with an ADD

I define aging parents as those over the age of 60 years. Other studies and papers have used this marker (Heller & Kramer, 2009; Heller & Caldwell, 2006) and 60 years of age and older is associated with life changes such as retirement and health problems (Seltzer et al., 2011; Heller & Caldwell, 2006). My review of the research studies quoted in this paper show the mean age of parents participating in studies is usually over the age of 65 years (Yoong & Koritsas, 2012; Taggart et al, 2012; Joffres, 2002).

Prevalence of ADDs living in the family home

Studies have shown the situation of ADDs and aging parents co-residing is common but the prevalence rate varies widely. Co-residing is not a static situation and, as the family ages, the percentage who continue living together decreases (Weeks et al., 2009). A US study by Heller and Caldwell in 2006 states that 25% of households with co-residing ADD are headed by members over the age of 60 (Heller & Caldwell, 2006). Using Wisconsin Longitudinal Study data, Seltzer et al. (2011) found that 39% of ADDs lived at home with aging parents compared to 2% for non-disabled adult children. In a cross-Canada study using focus groups of parents aged 60 to 86 years, 80% of ADDs lived with their parents (Joffres, 2002).
Defining the scope of the research problem in BC is hampered by the dearth of available statistics and, as a result, I will present an estimate as follows. The number of ADDs in BC are only tracked when they have received CLBC services and CLBC does not record the age of the caregivers. Using CLBC estimates (CLBC, 2014), a low approximation of ADDs over the age of 40 is 22,500. Generalizing that most parents of children aged 40 years or older would themselves be 60 years or older, and applying the percentages from the previous paragraph, there are between 8,700 and 18,000 families where ADDs live with aging parents. Studies suggest that less than half of these families have a future plan (Joffres, 2002; Heller & Caldwell, 2006).

2.2. The current government policies

As stated in the introduction, there was a paradigm shift approximately fifty years ago towards the care of individuals with developmental disabilities. Previously, parents of a child with a developmental disability were faced with relinquishing their child to an institution or supplying all the care themselves (Gross et al., 2012); an all-or-nothing government support scenario. Deinstitutionalization has resulted in a hybrid-support model where families and government both supply supports, through some literature suggests the bulk of support is from the parents (Burke et al., 2012; Yoong & Koritsas, 2012).

The current government stance towards people with a developmental disability provides the context in which future planning operates. The stance often reflects the broader societal approach to people with developmental disabilities. Families that need to have a future plan are directly affected. This section presents an overview starting from the global level to the provincial level.

2.2.1. The UN Convention of the Rights of Persons with Disabilities

The UN Convention of the Rights of Persons with Disabilities sets the global standard for the governmental approach to providing supports to ADDs. Two articles apply to future planning. Article 19- Living independently and being included in the community states society should ensure disabled persons have access to a range of
residential choices, not be segregated, and have access to services that support them in their living arrangement decision (UN, 2007). **Article 28- Adequate standard of living and social protection** states people with disabilities should have access to programs and public housing (UN, 2007). With respect to Canada, health and social programs are the responsibility of the provinces, and the government of BC has pledged to uphold the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) that Canada ratified on March 10, 2011 (SDSI, 2014). As a result, BC government policies, regulations and practices are evolving to uphold the rights of people with developmental disabilities in line with the UNCRPD.

### 2.2.2. The current disability system in BC

Future planning exists within the provincial system that supplements parental supports with government resources. The province of BC has a comprehensive and complicated system for providing housing and services to citizens with a disability. Government agencies that provide or manage services for the disabled are: BC Housing, Community Living BC, WorkBC, the provincial health authorities, and the Public Guardian and Trustee of BC (BC Gov't, n.d.).

**Community Living BC**

Community Living British Columbia (CLBC) is the government agency that controls government-funded services for adult British Columbians with a developmental disability. The philosophy behind CLBC is that society has a responsibility to care for ADDs and government supports supplement the community and family caregiving (Queenswood Consulting, 2011). The role of CLBC plays in supplementing community and family caregiving is not understood by families who feel the government is obligated to supply supports (Queenswood Consulting, 2011).

Established as a crown agency in 2005 under the **Community Living Authority Act** (CLBC, 2014), the agency is funded by and reports to the Ministry of Social Development and Social Innovation (SDSI). The CLBC has 37 local offices in the province which are located in three regions: Fraser, Interior, and North; Vancouver Coastal; and Vancouver Island (CLBC, 2014). According to the CLBC 2013/2014
annual report, the budget for CLBC was $739.3 million and the average cost per registered ADD was $46,200 (CLBC, 2014). Parents wanting to access government-funded services as part of their future plan are required to contact CLBC. As of December 2013, there were 9,171 adults registered with CLBC who are assumed to be living in the family home (CLBC, 2014). There is an unknown number of individuals and their families who have not had contact or have lost contact with the government, however approximately 300 new adults, not transitioning from youth, register with CLBC each year, likely as a result of aging caregivers (CLBC, 2014). As more unregistered adults join the system and the demand for CLBC services increases, there is the risk that CLBC may not be able to serve all individual nor maintain the level of services due to fiscal challenges (CLBC, 2014).

While no government or CLBC policies on future planning exist, the consequences resulting from the lack of future planning and aging has been a concern to CLBC. Since 2006, CLBC’s annual report has stated that the caseload will rise as parents co-residing with ADDs age and parents face health challenges (CLBC, 2006). CLBC is challenged with the transition from parental care to government services because CLBC does not know when the transition will occur (CLBC, 2014). The annual reports also list aging caregivers as one cause of crises, usually associated with residential placement (CLBC, 2014).

CLBC-directed services are provided to only those ADDs who are in the system and only when the approved resources are available. Individuals are eligible for CLBC services if they are 19 years of age or older and meet the DMS-IV-TR criteria before the age of 19 (CLBC, 2010). The level of needs for ADDs are determined by using an assessment tool called Guide to Support Allocation (GSA). Ten areas of life (communication; personal care needs; relationships; day to day decision making; life decisions; staying safe and well-being; work and learning; interaction in the local community; complex health needs (including mental health); and understanding complex risks and actions) are assessed in the GSA on a scale of 1 (little support needed) to 5 (high level of support required) (Inclusion BC, 2010). In addition to the score of 5, there is a “flag” level for some of the areas that indicate the individual cannot function without support (Inclusion BC, 2010). Facilitators work with the ADD and family to create a
plan for CLBC-funded services (CLBC, 2014). Notably, facilitators are not assigned to an individual and there is no single point of contact (Queenswood Consulting, 2008). CLBC approves the application for services based on three interconnected criteria: the individual’s plan, the individual’s GSA on file, and whether the requested service is listed in the CLBC’s Catalogue of Services (CLBC, 2014). If the request for service is for an emergency situation or the services are less than $6,000 per year the requirement for an individual plan can be waived. CLBC funds services such as residential living (shared living or group home), respite, home services, and support for caregivers such as homemaking services (CLBC, n.d.); requests for health services, education or income support are not services within the mandate of the CLBC (CLBC, 2014). The support requests are then placed on a regional Request for Service List (RFSL) and these requests are filled dependent on considerations such as the urgency of the need, available government funding, available resources, number of services the individual currently receives, and the status of others on the waitlist (CLBC, 2014). Individuals co-residing with aging parents are considered a priority group according to the CLBC resource allocation policy (CLBC, 2014).

The CLBC does not directly provide services to ADDs but contracts out the services to non-profit societies and for-profit enterprises or funds the individual directly. Currently, over 3,200 different service providers are contracted to provide services to the ADDs (CLBC, n.d.). The service providers often service a geographical area and families are served by the local providers. The contracts are defined by the Client Service Agreement and the Component Services Schedule with the CLBC acting as the agent for the ADD and their family (CLBC, 2011). Individualized funding allows the ADD and their family to act as their own agent.

The non-profit sector

Non-profits provide services such as day programs, life skills training, respite, housing, in-home support, independent living support and advocacy to enhance the lives of people with a disability and their families. The non-profit agencies and organizations providing these services for the disabled often have direct contact with families with an ADD. The funding for non-profits is on a continuum from those whose budgets are fully paid by the provincial government, to those who receive partial funding or grants, to
those paid only for the services they provide, and those that rely on non-government funding such as donations from the public (DDA, 2013). A simplified visual of the government-funded support system in BC for ADDs and their aging parents is presented in Figure 1.

Figure 1. Organization of BC’s disability system (w/o individualized funding)

![Diagram showing the organization of BC's disability system](image)

2.3. Factors that influence future planning by parents

This section looks at the literature on future planning and provides an overview of influences and barriers. My literature search was conducted through the Simon Fraser University Library system, Google and Google Scholar. Within these resources, I obtained peer-reviewed journal articles, newspaper articles, non-government reports and government reports using the following search words (and their close derivatives): “developmental disability”, “intellectual disability”, “mental retardation”, “learning disabilities”, “future planning”, “succession planning”, “barriers to planning”, “influences on planning”, “aging caregivers”, “aging parents”, “aging parental caregivers”, “disability services”, “non-profit disability services”, “government disability services”, “disability supports”, “housing for disabled”, “home share”, “supports for parents”, “adult child”, “dependent adult”, “siblings of a disabled sibling”, and “caregiving in families”. In addition, I also search for specific names or words related to the jurisdictions, government tools (such as RDSP and DSP), government agencies, and non-profit agencies. I selected only literature that was recent, starting in the year 2000, because I feel these articles used more recent research reflecting the societal changes in demographics and family composition.

In reading this section, it should be noted that each family experiences different factors that impede or encourage future planning. There is no consensus on what
factors motivate aging parents to engage in future planning nor to what extent certain factors play a role (Joffres, 2002). However, the information in this section represents common themes that appear in studies on future planning in Canada, USA, Australia and Northern Ireland. Lack of information, distrust of government, long waitlists for services, lack of housing options, the role of parenthood, and low savings act as barriers to future planning. Factors that encourage future planning are the parent’s state of health and siblings. When available, CLBC information is presented to give a BC perspective.

2.3.1. Lack of information

The process of future planning is negatively impacted by the lack of information. Parents feel the government fails on several fronts: in providing information on available services, making information easy to find and making the information easy to understand (Joffres, 2002; Taggart et al., 2012). Parental perception that housing and services provided by government are difficult to determine will reduce their efforts in future planning (Jokinen et al., 2012; Heller & Caldwell, 2006). The CLBC satisfaction survey has shown that ease of access to information by families with ADD is an issue; in 2011 only 47% were satisfied with the level of access to information (Mustel Group, 2011).

While the literature review agrees that parents want more information to use for planning, the outcomes of providing more information is not clear. In one intervention utilizing workshops in future planning, The Future is Now, found that one year later 76% of participating families enrolled had written a letter of intent\(^2\) and 64% had started residential planning (Heller & Caldwell, 2006). However, in an Ontario study, service providers note that despite the urgency of future planning that many parents fail to act regardless of the information provided and appeared to be unconcerned about future planning (Salvatori et al., 2003).

\(^2\) A non-legal document found in the US outlining the needs of the dependent individual and the plan for the future
2.3.2. Distrust of government

In Canada, studies have shown that parents do not fully trust the government to provide the best care for their child (Weeks et al., 2009; Joffres, 2002) and the lack of trust makes future planning difficult (Salvatori et al., 2003). Government agencies and parents have two different perspectives regarding the needs of the ADD. The government employees seek to meet the requirements of eligibility and needs based on measurable criteria such as levels of disability. In contrast, parents feel the needs are based not only on disability but on all factors and individual characteristics that affect daily functioning (Joffres, 2002). One result of this mismatch of expectations is that parents do not feel heard or understood by the government (Allen Consulting Group, 2009; Weeks et al., 2009). In BC, the use of the GSA to determine the level of service and supports can be problematic because CLBC is slow or reluctant to reassess adults with developmental disabilities as the individuals age (CLRP, 2008). Parents limit their interactions with the government as a result of the lack of confidence they have in the government (Joffres, 2002). Even when the government programs and services are well-received, parents doubt the permanency of any program due to elections and budgets (Joffres, 2002).

2.3.3. Waitlists

One of the major reasons aging parents do not trust the government is the parent’s perception that the system is underfunded resulting in waitlists. Parents perceive the government’s lack of funding as a denial of service (Yoong & Koritsas, 2012). Waitlists exist in all provinces and in the US (Heller & Caldwell, 2006) for housing and for home care. In the 2011 CLBC satisfaction survey, timeliness of the services provided by CLBC was satisfactory for only 51% of families with an ADD (Mustel Group, 2011). In response to the question of how long people waited for services, 62% of families indicated that they have waited more than one year for requested CLBC services and, of those, 29% have been waiting longer than 3 years (Mustel Group, 2011).

The long waitlists for government-funded supports are a significant factor in families making future plans because parents cannot be sure the services will be
available when needed (Yoong & Koritsas, 2012). Suitable housing and services are not available even after years of waiting on the list (Jokinen, et al., 2012). Given the demographics of ADDs and their parents, the demands on government resources will grow (Burke et al., 2012). Even when future plans are in place the long waiting lists proved to be quite a detriment to a smooth transitions when the plans need to be enacted (Jokinen et al., 2012). The significant wait period undermines confidence that a future plan can function (Allen Consulting Group, 2009). Parents perceive government supports as being crisis-driven; moving forward in planning is hindered by waitlists and government action occurs only when the situation becomes urgent (Jokinen, et al., 2012; Yoong & Koritsas, 2012).

2.3.4. Housing and residential services

One of the most anxiety-provoking barriers to future planning for parents is the consideration of residential arrangements and the care associated with that residence (Heller & Caldwell, 2006; Yoong & Koritsas, 2012; Joffres, 2002). Keeping the aging parents and ADD together in the family home is preferred (Taggart et al., 2012) but this arrangement is prolonged when there is not access to alternative residential arrangements (Jokinen et al., 2012). Housing and outside-care concerns are tightly related. First and foremost, parents worry about the future care of their son or daughter and want a place for their child to live where they will be loved and properly cared for (Weeks et al., 2009; Allen Consulting Group, 2009). Other parental concerns are that movement to a new residential setting could lead to the loss of social relationships within the neighbourhood of the family home which are very important to the well-being of the ADD (Weeks et al., 2009; Joffres, 2002; Yoong & Koritsas, 2012) and the routines could be different from the family home (Jokinen et al., 2012). Parents feel helpless to ensure their child will end up in a suitable location under government care (Jokinen et al., 2012).

The types of residences that parents deem suitable vary family by family but often the preferred housing is not available. In a study on housing in Prince Edward Island, Weeks et al. (2009) found parents preferred living arrangements where four or fewer ADDs lived together or where the ADD and parents could age-in-place together. If the ADD has co-morbidity conditions or aging issues, parents do not spend time on
future planning for residence because parents feel their choice for housing either does not exist in their community (Taggart et al., 2012) or their child would not be eligible for their selection (Joffres, 2002). Some aging parents have responded to the lack of suitable housing by creating their own accommodation for their ADD (Joffres, 2002).

2.3.5. Parental beliefs and values

The beliefs and values that parents hold about their role in their child’s life play an important part in how they view future planning. One of the most basic beliefs, regardless of whether disability exists, is the parent’s identity as a caregiver for their children. For parents of an ADD, being the caregiver is their identity (Yoong & Koritsas, 2012) and enacting a future plan or starting a future plan is a threat to this identity (Joffres, 2002). Parents, especially mothers, are often very reluctant to have their child leave the family home because they fear the care will not be as good as what they provide (Jokinen et al., 2012; Taggart et al., 2012). Parents also receive satisfaction and companionship from providing caregiving to their child (Heller et al., 1997; Yoong & Koritsas, 2012; Salvatori et al., 2003) and future planning, especially residential planning, implies these factors would decrease. If the ADD was to leave the family home, the parent’s role would need to be adjusted at a time when changes are often traumatic (Taggart et al., 2012).

2.3.6. Low income and savings

Aging parents may feel their lack of savings and low income limits their options when they consider future planning. Parents caring for an ADD child often struggle financially (Yoong & Koritsas, 2012). In a study of families with ADD in Prince Edward Island, 27% of parents felt that their family income did not meet their needs (Weeks et al., 2009). The nature of caring for their daughter or son reduces parental ability to earn sufficient income needed to build savings (Seltzer et al., 2011; Yoong & Koritsas, 2012). Parents, particularly mothers, have lower labour participation rates of employment when compared to parents who do not have a disabled child (Seltzer et al., 2011). Parents who spend a lifetime supporting their disabled child have financial difficulties in paying for any future support required by their daughter or son (Weeks et al., 2009). The ADD
also has low income and often the only source of outside income is from government disability pensions (Salvatori et al., 2003) and this too limits planning options.

2.3.7. Health and mental state of parents

Dealing with their own physical and mental health issues can encourage aging parents to undertake future planning for their ADD. However, there are two contrasting responses by parents to these challenges. Joffres (2002) states that for some families, aging changes do encourage future planning but, in other cases, the increased vulnerability had the opposite effect. Regardless, this push factor is strongest when the situation is dire (Taggart et al., 2012).

Often parental aging does affect the ability of the parents to provide caregiving and motivates parents to plan for the future provision for their child. While families may manage with a child with a disability when the parents are relatively young, Seltzer et al. (2011) showed that problems with health, psychological functioning, and a lower level of social involvement emerged when the parents were 60 years of age or older. In opposition to the caregiver satisfaction noted in section 2.3.5, aging parents perceive the physical and mental demands of caregiving as significant (Taggart et al., 2012). Depression is common in aging parents caring for ADDs in comparison to other seniors (Heller et al., 1997; Seltzer et al., 2011). In an Ontario study of 154 families in 2012, 45% of the parents had a medical or physical condition (Ouellette-Kuntz, et al., 2014). Parents who have a mental or physical health problem of their own are less likely to cope with any crisis situations (Ouellette-Kuntz, et al., 2014) making it more necessary to plan a future in which their child is well-supported. When aging or health issues become too pressing and the parents are no longer able to take care of their disabled child, agencies are needed to step in to provide the care (Weeks et al., 2009; Taggart et al., 2012). Parents will sometimes request a government-funded respite that provides parental caregivers with a short break from caregiving (Lund, et al., 2014).
2.3.8. Siblings as caregivers

As the parents age, siblings of the ADD are instrumental to facilitating and participating in the future plans. Siblings often start the conversation in the family about future planning (Jokinen et al., 2012). In some cases, the ADD may not have a sibling (Ryan et al., 2012), but, where a sibling exists, parents diverge on two fronts. On one front, aging parents do not want to burden their other children or feel that the sibling is not prepared to take over caregiving (Joffres, 2002). On the other front, many parents assume that the care of their ADD will be taken over by the siblings of that child or by other family members (Weeks et al., 2009; Heller & Caldwell, 2006). Regardless of the assumptions, it is common for parents to name one of their non-disabled children as a guardian or trustee of their ADD (Heller & Kramer, 2009).

There are several challenges to future planning when considering siblings as caregivers. While most parents recognize that future planning must involve the cooperation or acknowledgement by other family members, especially siblings, many parents do not discuss this issue (Heller & Caldwell, 2006; Burke et al., 2012; Heller & Kramer, 2009). Siblings are often unaware of the future plan and their role. Whether siblings can, or will, take over caregiving depends on issues such as: being female, being the only other sibling, their age, having a close relationship and living close-by (Burke et al., 2012; Heller & Kramer, 2009). The age of the non-disabled sibling is relevant; a study of 757 siblings across the US found when the non-disable sibling was 40 years or older they were less likely to plan on being long-term caregivers to their sibling with a developmental disability (Burke et al., 2012). The implication for aging parents with a co-residing ADD is that future planning needs to incorporate supports from outside the family.

2.4. The state of future planning in BC

No studies have been undertaken to examine the status of future planning in BC. It is reasonable to assume that the factors presented in section 2.3 are likely applicable to BC. Aging parents face barriers that they have difficulty overcoming when they need to plan for the future supports for their child. The increasing caseload observed by
CLBC resulting from parents ceasing their caregiving indicates that some parents do not have a future plan. Yet, factors specific to future planning by parents in British Columbia have not been researched. This study will examine future planning within BC in order to propose policy solutions that will ensure an optimal outcome for the ADD and reduce the crisis caseloads for CLBC.
Chapter 3.

Methodology

3.1. The research questions

The background review and the literature review illuminated the extent and context of the policy problem that too few aging parents have a future plan. Clearly, the problem is recognized across Canada, the United States and other western countries. Journal articles espoused and supported a variety of different reasons why parents are not carrying out planning. While families are primarily affected by the lack of future planning, governments and service providers are also stakeholders. Given the setting of my policy problem is confined to BC, my research asks two main questions:

1) What do stakeholders perceive as influences/constraints on planning for the future by parents who take care of co-residing ADDs, within the province of BC?

2) What can social care services and the government do to encourage parents to have workable future plans known to service providers?

3.2. The methods

Two types of qualitative methodology are used in this study to address the research questions: semi-structured interviews and case studies. Only qualitative methods were used to explore future planning in for two reasons. First, future planning is sensitive topic and the ability to minimize any emotional turmoil was prudent. Controlling the risk to parents is explained further in section 3.2.1. Secondly, the literature review indicated there were many factors influencing future planning and qualitative methods, especially semi-structured interviews, allowed for discovery of the
factors relevant to BC. The purpose of the interviews is to explore the perspectives of different stakeholders on the issues or constraints they feel exist within the current system in regards to future planning. The purpose of the case studies is to examine what different jurisdictions do to support aging families with an ADD and what they currently do to encourage future planning. Semi-structured interviews and case study analysis complement each other and provide a ‘fit’ to explore the current status of future planning (Galletta & Cross, 2013). The semi-structured interviews present the micro or singular view point of future planning. The case studies present the aggregate (Yin, 2009) or macro view of future planning. Both the semi-structured interviews and the case studies (Yin, 2009) yield contemporary data.

3.2.1. Risk management

Future planning is a sensitive topic; it implies that, at some point in time, the aging parents will die or face a health issue so substantial that their ability to take care of their child must end (Taggart et al., 2012). Semi-structured interviews and case studies allowed for examination of barriers to future planning while not increasing the risk to any of the stakeholders. Informed consent was obtained from all interview participants. Additionally, parents who were interviewed were referred to me by a non-profit service group and each candidate was asked if they had completed a future plan or were in the process of doing a future plan or had attended a workshop on future planning. The case studies conducted for this project did not put any of the stakeholders at risk because they used public documents and public webpage domains.

3.3. Semi-structured interviews

The semi-interviews provided insight of how the current system of parental and government support works, the perceived barriers to future planning in the current system and possible changes that can improve future planning. Interviews were conducted with the three stakeholder groups: parents of an ADD, government officials, and non-profit employees. In many cases, those who work in organizations associated with developmental disabilities also have a close relative who is developmentally disabled, including a daughter or son. For the purpose of representing service providers,
non-profit organizations were selected because of their visibility and accessibility in the community. Individuals who were working for CLBC or for SDSI represented the government stakeholder position. Interviews were also conducted with experts living in BC to provide a non-biased viewpoint. The government interviews also informed the case studies. Semi-structured interviews present the viewpoints of the stakeholders in a contemporary timeframe. Semi-structured interviews allowed the interviewees to answer the questions the interviewer might pose but more importantly, to provide new insight into the topic (Galletta & Cross, 2013).

The details of the semi-structured interviews are:

<table>
<thead>
<tr>
<th>Stakeholder</th>
<th>Number of interviewees</th>
<th>Interview Schedule</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parents of an ADD</td>
<td>5</td>
<td>Appendix A</td>
<td>Appendix E</td>
</tr>
<tr>
<td>Government Employees</td>
<td>4</td>
<td>Appendix B</td>
<td>Appendix F</td>
</tr>
<tr>
<td>Non-profit Employees:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Service providers</td>
<td>• 4</td>
<td>Appendix C</td>
<td>Appendix G</td>
</tr>
<tr>
<td>Advocates</td>
<td>• 2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Planning specialty</td>
<td>• 1</td>
<td></td>
<td></td>
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<tr>
<td>Experts:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gerontology</td>
<td>• 1</td>
<td>Appendix D</td>
<td>In text</td>
</tr>
<tr>
<td>Disability</td>
<td>• 1</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### 3.3.1. Conditions of the semi-structured interviews

The semi-interviews were conducted from January 8, 2015 to February 25, 2015. The location of the interview was determined by mutual consent between the researcher and participant; eleven interviews were conducted face-to-face and seven interviews were conducted over the telephone. On average, interviews were one hour long; the interview durations ranged from 25 minutes to 1 hour and 30 minutes. The interview questions were derived from the literature review and the background (Galletta & Cross, 2013). The interview schedule containing the questions was sent to the participant prior to the interview.
Analysis of the interviews used the thematic analysis to reveal findings. Each interview was transcribed word for word with the exception of the telephone interview call to Australia. The printed transcription was coded using thematic analysis using the approach outlined by Braun and Clarke (Braun & Clarke, 2006). The printed transcripts were also imported into NVivo and recoded for keywords and themes. Codes within a stakeholder group were often the same in response to the issue being discussed and these patterns indicate a common viewpoint (Galletta & Cross, 2013). Themes were discerned from common codes that addressed the research questions and the topic of future planning (Braun & Clarke, 2006). After many coding passes, the hand-coded transcripts provided the larger themes and the NVIVO reports verified those themes.

3.3.2. Limitations of Semi-structured interviews

The small number of parents with similar socioeconomic backgrounds presents a challenge to the external validity of the findings from these interviews, but at the same time these parents were well-positioned to represent their stakeholder group. The parents shared very similar characteristics: they appeared educated, recently retired or ‘slowing down’, lived in urban or suburban areas in the lower mainland/Vancouver Island and ranged in age from the mid-60’s to early 70’s. Their child with a developmental disabilities ranged in age from in their 30’s to 40’s and lived outside of the family home. However, first and foremost, these parents provided a retrospective of a successful future plan: they had set up RDSPs and trusts to provide financially for their child; they had successfully obtained a place for their child to live; and they had a plan to replace the caregiving they provided to their child. Also, the parents that were interviewed were articulate, connected to other parents with an ADD and mindful of the struggles in future planning. Five interviews were sufficient because, as the interviews progressed, very similar viewpoints were expressed.

3.4. Case studies

My case study methodology takes an exploratory multi-case approach (Yin, 2009). Case studies seek to answer the research questions at an aggregate level (Yin, 2009). Complementing the semi-structured interviews, the case study methodology
examines the bigger picture of future planning; case studies present the context at the mid-government level in which future planning operates and the influencing factors at this level. The propositions for my case study approach are as follows. The first research question regarding possible barriers to future planning can be illuminated by looking at: the current supports for ADDs in the jurisdiction; the current supports for families with an ADD; and future planning on the political/social agenda. The research question looking into ways government can encourage future planning looks at innovations and unique practices in future planning.

3.4.1. Selection of jurisdictions

Selection of jurisdictions for case studies followed the following criteria: the level of study was at the provincial/state because the responsibility for ADDs is set within provincial boundaries; progressive societal attitude to people with disabilities; similar social-economic characteristics; and government involvement in service or income provision for vulnerable populations. My study investigates the status of future planning in three jurisdictions, each in a different country: Canada/British Columbia, Australia/Queensland and USA/Washington State. Refer to Table 2 for case study information.

3.4.2. Sources of case study information

Information for case studies were derived from websites, written documents and semi-structured interviews with individuals who worked for governments. Written information such as government reports were sourced primarily through government websites. Websites and internet searches provided gray-source information from newspapers and non-profit organizations. The purpose of the interviews was to gather information on trial programs and to confirm my interpretation of the current system serving adults with developmental disabilities. The interviews with the four BC government workers took place at government offices. An interview with a government official in Queensland for the purpose of gathering information about the Elderly Parent Carers Initiative Trial (EPCIT) was conducted via a telephone call.
Table 2. Characteristics of jurisdictions for case studies

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>British Columbia</th>
<th>Queensland</th>
<th>Washington State</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Type of government</strong></td>
<td>Federalism, Article 92 of Constitution Act 1982 gives provinces jurisdiction over social services (Dept of Justice)</td>
<td>Federalism, In Commonwealth, State and Territory Disability Agreements, the Commonwealth is responsible for income assistance leaving management of services and policy to the states (DSS, 2014).</td>
<td>Federalism, State government have powers over health and social systems, strong division of powers but Title XIX – Grants to States for Medical Assistance allows for federal funds and control in state services.</td>
</tr>
<tr>
<td><strong>Progressive attitude</strong></td>
<td>• Federal gov’t ratified UN Convention on Rights of Persons with Disability – March 2011</td>
<td>• Federal gov’t ratified UN Convention on Rights of Persons with Disability – July 2008</td>
<td>• Federal gov’t signed but did not ratify the UN CRPD.</td>
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<tr>
<td></td>
<td>• Annual Income: CA$54,000 (Govt of Canada, 2011)</td>
<td>• Annual income: AU$64,000 estimate (ABS, 2012)</td>
<td>• Annual income: US$59,478 (USCB, 2014)</td>
</tr>
<tr>
<td></td>
<td>• Percentage of population over 65 yrs: 15.7% (Govt of Canada, 2011)</td>
<td>• Percentage of population over 65 yrs: 13.2% (ABS, 2013)</td>
<td>• Percentage of population over 65 yrs: 13.6% (USCB, 2014)</td>
</tr>
<tr>
<td><strong>Gov’t provision</strong></td>
<td>• Person With Disability pension</td>
<td>• Federal: Department of Social Services</td>
<td>• Supplemental Security Income, HCBS waivers.</td>
</tr>
<tr>
<td></td>
<td>• Crown Agency: Community Living BC</td>
<td>• State: Disability Services that is part of Department of Communities, Child Safety and Disabilities.</td>
<td>• Developmental Disabilities Administration – part of Department of Social and Health Services</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Disability Support Pension provided</td>
<td></td>
</tr>
<tr>
<td><strong>Full Case Study</strong></td>
<td>Appendix I</td>
<td>Appendix K</td>
<td>Appendix M</td>
</tr>
<tr>
<td><strong>Information Sources</strong></td>
<td>Appendix H</td>
<td>Appendix J</td>
<td>Appendix L</td>
</tr>
</tbody>
</table>
Chapter 4.

Findings

Briefly, I present the findings of the semi-structured interviews and the case studies in the sections 4.1 and 4.2 respectively. The combined findings presented in section 4.3 provide the overall themes that were revealed in both type of methods used.

4.1. Semi-structured interviews

This section briefly presents the findings from the semi-structured interviews conducted with the three stakeholder groups: parents, government employees and non-profit employees. The findings relate back to the research questions. The stakeholder perspectives are presented on the perceived barriers to future planning in the current system and possible changes that can improve future planning.

4.1.1. Findings from the interviews with parents

Parents were in the unique position of providing their experiences in starting a future plan and their progress to date. The overall theme “best practices” is synonymous with improvement to future planning, albeit at a micro level. Below is a brief synopsis of the themes and a more complete report is found in Appendix E.

Best practices:

- Start early because supports take time to put into place. Future planning is a process but eventually supports will fall into place.
- Future planning will never take away all the worries of being a parent to an ADD but parents feel better knowing some supports are in place.
- Advocate for your child.
• Be open to the information about future planning. Attend workshops given by organizations.
• Know and trust in your child. Prepare them for an 'independent' life.
• Families should take advantage of the RDSP.
• Families should set up representation agreements and trusts.

**Barriers to future planning:**

• Support networks that will provide informal caregiving are difficult to manage.
• The level of future caregiving worries parents. Government-funded care is critical to a future plan succeeding.
• Lawyers do not always understand how to set up wills and trusts for people with disabilities.
• A low income makes it difficult to save for the future.
• The DTC application is difficult, yet without the DTC parents cannot set up an RDSP.
• There is a lack of choice for government funded housing. Homeshare does not fit all ADDs.
• The waitlists for housing is too long and the most common way to get housing is to be in a crisis situation.
• Care-giving is exhausting and parents do not have energy for planning.
• Parents do not know how to plan or are afraid of planning. There needs to be more information.

**4.1.2. Findings from the interviews with government employees**

Government employees provided a different picture of future planning. Less of the discussion was directed at future planning and more discussion was on the current government services. The improvements to future planning are found in the case studies. The following is a summary of the themes and a more complete report is found in Appendix F.
**Government limitations:**

- CLBC services are not mandated. Government services are meant to supplement not replace the caregiving the ADD receives from their family and community.
- Funding cannot cover the demand for services and supports. The system is crisis-driven.

**Barriers to future planning:**

- Some service providers lack the capacity to provide all types of services in different parts of the province.
- Managing a support network is difficult for parents and informal support networks do not include government and professional members.
- Families are the only entity who can undertake financial planning for the future.
- Families may be unaware of the transition from PWD to OAS and GIS when the ADD turns 65 years old. Applications must be submitted to make the transition.
- The lack of housing can cause two problems: 1) the loss of permanency makes it difficult to track medical problems from the disability and 2) ADDs may be placed in long term care for lack of housing.
- Not all housing is suitable for aging-in-place.
- Parents do not know how to start future planning.
- Some parents do not know the role of CLBC and have never received services.

**4.1.3. Findings from the interviews with non-profit employees**

Employees of non-profit organizations provide a comprehensive perspective of future planning. Non-profits are intermediaries between parents and CLBC; employees understand parental concerns about current and future services but also see CLBC trying to fulfill its purpose while holding the line on increasing costs. Non-profits echoed improvements to future planning found in both parent and government interviews but
never clearly stated improvements. Below is an overview of the themes and a more complete report is found in Appendix G.

**Non-profit observations:**

- The system is crisis driven. When there does not exist a known future plan, non-profit organizations do ‘the best they can’ to find accommodation and services.
- Funding cannot cover the increasing demand for services and supports.
- Future planning is an ongoing process.
- Non-profits are instrumental in providing information and easing parents into planning for the future.
- Setting up financial planning is a chore for parents but easy to maintain and rewarding for the ADD.

**Barriers to future planning:**

- Parents find it hard to accept that future caregiving for their child will come from others. Parents strongly identify as the only caregivers for their child.
- Support networks are difficult to maintain and parents have not fully engaged others in the support plan.
- ADDs need life skills training and greater independence in order to be prepared for life without their parents’ caregiving.
- Waitlists hinder progress on future plans.
- Many parents do not understand legal representation for ADDs.
- Trusts and wills need to be correctly arranged and trustees also need to be carefully chosen.
- Families do not have incomes to pay for future services and ADDs do not have incomes that allow for independence.
- Housing choice has been limited to home-shares but this may not be suitable for aging-in-place.
- Government supplied services may not be available to help ADDs live in parental-supplied housing.
- Aging parents are often exhausted from caregiving.
- Parents do not want to start or do not know how to start future planning.
• Parents either have never used CLBC services or over-estimate the capacity of CLBC to fund services.
• Parents and governments do not use the same terms for communicating their position.

4.2. Case study findings

This section reviews the overall findings of the case studies conducted on British Columbia, Queensland, and Washington State. The findings answer the propositions presented in Section 3.4: the current supports for ADDs in the jurisdiction; the current supports for families with an ADD; future planning on the political/social agenda; and innovative or unique policies aimed at future planning.

4.2.1. Case study: British Columbia, Canada

Current supports for persons with developmental disabilities

The current supports for ADDs provided in BC primarily come from the family and provincial government with the federal government providing a lesser role. The supports can be divided into financial/legal, service and housing supports. The following are the supports provided within BC.

Financial supports
• The Persons With Disability pension (PWD), funded by the government of BC, provides CA$531.42 per month plus an additional CA$375 shelter allowance. The PWD is income and asset tested. The pension is necessary because employment opportunities are minimal and jobs that do exist are often part-time and poorly paid (SPARC BC, 2009).
• The federal government provides the Disability Tax Credit through the Canada Revenue Agency, and if eligible, can claim up to CA$7,766 in non-refundable tax credits (CRA, 2014).
Service supports

- CLBC is constricted by its budget provided by the provincial government and is well aware of the shortfalls as it deals with climbing costs and an increasing population (CLBC, 2014).

- One of CLBC’s goals is to increase the number of people using individualized funding (CLBC, 2014). There are two formats for choice-based funding: 1) direct funding where the individual or agent is given the CLBC allotment to manage and 2) host agency funding where the individual or agent chooses a service provider and CLBC gives the allotment to the service provider to manage (CLBC, 2009).

Housing

- CLBC funds three types of housing arrangements: home shares (shared living), group homes (staffed residential), and cluster living (supported living) (CLBC, 2014; SPARC BC, 2009). In 2014, two-thirds of the 6,564 adults receiving residential services resided in shared living or supported living settings and the remaining third were in group homes (CLBC, 2014). CLBC is promoting home share.

- Non-profits provide the housing and service supports to families. In 2008, there were 54 non-profit housing societies that provided 889 housing units designated for people with developmental disabilities (SPARC BC, 2009). These units served approximately 4% of the 20,130 adult population with a developmental disability (SPARC BC, 2009). Housing for aging-in-place is lacking.

The current supports for families with an ADD

- CLBC provides CA$2,800 a year through the Adult Respite Direct Funding to each registered ADD. Families may choose any service provider, neighbour, friend, or relative to provide respite providing provincial regulations are adhered (CLBC, 2007).

- Non-profit organizations facilitate parent-support groups and provide workshops.

Future planning in the political/social agenda

- While the CLBC has consistently recognized that aging parents with ADDs will need services in the future, policies or approaches to future planning have not been
created. There is a brochure and a webpage on aging created (CLBC, 2010) but the webpage is not easy to find.

- The RDSP is a federal initiative to encourage saving and is open to all people with a severe disability. The federal government contributes the Canada Disability Savings Grant and the Canada Disability Savings Bond. Overall, the uptake of the RDSP has been approximately 78,000 of the 500,000 eligible Canadians (Hodges, 2014).

- The *Representation Agreement Act* allows an ADD-selected representative to legally make decisions on behalf of the ADD (CBA, 2012). There are two types of representation agreements: RA7 and RA9 (Nidus, 2012).

- Several non-profit organizations specialize in planning for adults with disabilities with a focus on financial planning and support networks. For each of these organizations, there is a fee for maintaining the support network and, due to the nature of networks, the organizations are limited geographically.

**Innovative or unique policies aimed at future planning**

- Services to Adults with Developmental Disabilities (STADD) for persons over the age of 55 years is a prototype program directed at helping aging ADDs. Currently the program is only offered in Burnaby, BC. The STADD navigators assist individuals and their families to engage in the current system and prepare for the future (CLBC, 2014). A navigator meets with individual, and records their goals and information about their needs into a database called COLLABORATE (Government interview). Given the needs and goals of the individual, the navigator convenes a meeting with the personnel from different organizations and from informal networks. The members at the meeting may be from the Ministry of Health, CLBC, service providers, friends and family. Along with the ADD, the navigator presents the needs to the members at the meeting and the group works as a team to support the plan (Government interview). The group becomes an integrated support network, combining both the informal support network of family and friends with the formal professional support network (Government interview). Different group members volunteer to take on duties or tasks to support the ADD. The navigator provides follow-up, notes the progress on the tasks, updates COLLABORATE and makes
adjustments to the plan. STADD has no funding or authority but can bring both the formal and informal support teams to work together (Government interview).

- **Strategy on Aging** is project involving CLBC, other ministries and service providers to support aging ADDs and their families. Workshops and forum were held across the province for parents, CLBC employees, and service providers to encourage a proactive approach to aging, including future planning.

### 4.2.2. Case study: Queensland, Australia

**Current support for persons with developmental disabilities**

People with disabilities receive supports through the Commonwealth Department of Social Services (DSS) and the State Department of Communities, Child Safety and Disabilities (DCCSD). People with intellectual disabilities are not distinguished from other disabilities for the purpose of accessing government support and services (Allen Consulting Group, 2009).

**Income support from government**

- The Commonwealth provides the Disability Support Pension (DSP). The current DSP is a maximum of AU$776.70 per two weeks (HS, 2015) (approximately AU$1,680 per month). In addition, there is an automatic pension supplement of AU$63.50 every two weeks (AU$137 per month) (HS, 2014). The DSP is asset and means tested.

**Housing and service supports**

- The DSS has been advancing the National Disability Insurance Scheme (NDIS) policy for a country-wide acceptance in 2016 (DSS, 2015). The family and individual with a disability choice will be able to choose their services and service providers (QLD Govt, 2014). However the NDIS has received mixed reviews on its impact on aging families. The NDIS is seen by some as a way to increase the support for older families (Copland, 2012), but others fear the NDIS may freeze the funding provided and will not be adjusted as the parents get older (Visentin, 2014).
• The Queensland government provides funding for accommodation and direct-care disability services. The Queensland government does not provide most on-the-ground services but contracts out the services to non-profit and for-profit organizations. Regional offices of the DCCSD maintain the Register of Needs, a list of people waiting for specific services (Clerke, 2015).

• Non-profit organizations in Queensland provide advocacy for individuals with disabilities, advocacy for caregivers, employment services for the disabled, respite, day programs, housing, accommodation support and direct care services. To access the services of non-profits, individuals must be deemed eligible by the Queensland government.

• The Queensland government funds community housing but requires applicants to prove their current housing is unsuitable (QLD Govt, 2014).

**The current supports for families with an ADD**

• Australia has passed the Carer Recognition Act 2010 as a step in the National Carer Strategy to support care-givers (DSS, 2010).

• The Commonwealth dispenses the Carer Payment and the Carer Allowance to care-givers of adults with a disability. In 2014 under the Carer Payment, a care-giver can apply for and receive a maximum of AU$776.70 every two weeks (AU$1,682 per month) for a single caregiver or a maximum of AU$1,171 (AU$2,527 per month) for a couple providing care to a person with an eligible disability (HS, 2014). The Carer Allowance is AU$121.70 every two weeks (AU$263.68 per month) and is not means or asset tested (HS, 2014).

• The Australian government also supports respite services through the Home and Community Care program and the National Respite for Carers program (Allen Consulting Group, 2009).

• The Older Carer Initiative is a program in Queensland focused on aging families co-residing with an ADD. The program provides extra respite to carers who are 65 years or older (50 years or older for Indigenous carers) who are living with and caring for a person disabled who is less than 65 years old (DCCSDS, 2014). The respite can be
obtained through selected service providers or though government-run respite centres (Clerke, 2015). Families who use this program also receive counseling on future planning with regards to future housing (DCCSDS, 2014).

**Future planning in the political/social agenda**

Australia has been proactive on future planning through research, providing information to parents and the creation of the special disability trust.

- The government has undertaken several consultations with advocacy organizations and with parents to examine the issues within future planning. The Queensland state government promotes future planning on its government website under the categories *Support for Adults* and *Support for families, carers and friends*. The government provides a link to the Commonwealth booklet on Special Disability Trusts and a booklet produced by a non-profit organization called Pave the Way (QLD Govt, 2014).
- Special Disability Trusts (SDT) gives families or friends the ability to create funding and/or manage assets for an individual with a disability without interfering with the DSP (Allen Consulting Group, 2009; DSS, 2015).

**Innovative or unique policies aimed at future planning**

- The Elderly Parent Carer Innovation Trial (EPCIT) is a response to the lack of housing options for aging families co-residing with an adult child with a disability (Clerke, 2015). Through the Department of Communities, Child Safety and Disability services, the Queensland government is conducting EPCIT at a cost of AU$15 million over 3 years (DCCSDS, 2014). EPCIT provides capital grants for innovative projects addressing housing/accommodation for adults with a disability who are co-residing with parents who are 60 years and older. Successful proposals selected from calls to public tender and must be unique from other models on trial. Other criteria for proposals are: the organization must provide its own funds to the project, the project must not require new support funding, and the grant monies are subject to a mortgage that can be recalled if the project does not provide housing over the long run to the eligible population (Clerke, 2015). One of the underlying values of EPCIT is allowing the person with a disability to live as independently as possible.
and prepare for the time that the parents will no longer be able to provide caregiving. As of late fall 2014, 61 adults had been placed at a cost of AU$7.8 million (DCCSDS, 2014). More details on EPCIT are provided in Appendix K, The Queensland case study.

EPCIT addresses parental concerns on planning for accommodation. Parents perceive the lack of accommodation options as a barrier to future planning and a source of great stress (Visentin, 2014). Parents want a ‘home’ that suits their child, a residence that is in the local area allowing the individual’s needs to be met (N-Carta Group, 2007). Parents have criticized the government for offering a very limited selection of housing and not increasing the number of residences available, especially, housing allowing a small number of ADDs to live together (N-Carta Group, 2007).

4.2.3. Case study: Washington State, USA

Current support for persons with developmental disabilities

Income support from government

- Federal funding for persons with a disability is paid out through Supplemental Security Income (SSI) benefits through social security. Currently, a maximum of US$721 per month plus a state administered supplement is paid to all disabled persons who qualify for SSI (SS, 2014).

- The state dispenses the financial support in the form of the State Supplemental Program (SSP) as required by Title XIX. The amount paid out is provided as a cash benefit and SSP varies depending on the individual but the most commonly reported annual amount is US$900 per year (Elrod & Davis, 2014).

Housing and service supports

- Home and Community-Based Services (HCBS) waivers allow the state to use Medicaid funds meant for institutions-based services for community based services for people with a developmental disability (Williamson & Perkins, 2014). There are five types of HCBS waivers available to all ages of individuals with a
developmental disability in Washington: Basic, Basic Plus, Core, Community Protection and CIIBS.

- According to 2012 data, 11,480 individuals were on waivers with annual amounts ranging from $9,805 for Community Protection to $1,562 for the Basic waiver (Rolfe, 2012).

- The Developmental Disabilities Administration (DDA), part of the Washington State Department of Social and Health Services (DSH), manages services for ADDs. In 2012, out of the estimated 82,000 individuals eligible for DDA services, only 26,240 were receiving services (Rolfe, 2012).

- Community residential services are funded by the state and divided into facility-based (group homes and residential care) and non-facility-based (supported living or home share, family home and tenant support).

- Nearly 75,000 or 70% of individuals with a developmental disability live with a family caregiver, while the remaining 30% are equally split between residential care and living alone or with a roommate. Further, it is estimated that 17,000 of those living at home are with caregivers who are older than 60 years (State of States, 2011).

**The current supports for families with an ADD**

- Individual & Family Supports funding covers respite and for parents and family caring for a person with a developmental disability but is primarily used as a crisis fund (ARC, 2013).

- Family Caregiver Support Program of Washington State is a policy from the Aging and Long-Term Support Administration and operated by the local chapters of the Area Agency on Aging (DSHS, n.d.).

**Future planning in the political/social agenda**

- Developmental Disabilities Life Opportunity Trust (DDLOT) allows families to set up assets that would not interfere with an individual's SSP or HCBS funding (DDLOT, 2011).
• Non-profit organizations are active in future planning. LifeSPAN manages support networks. The ARC, a national advocacy group for people with a developmental disability, has published booklets and created webinars on future planning over the past decade.

**Innovative or unique policies aimed at future planning**

• The Arc has implemented a website, Center for Future Planning, dedicated to future planning. The website, which was launched in December 2014, caters to parents, siblings, friends and professionals. Different webpages list topics for discussion, resources, and examples (ARC, n.d.).
4.3. Combined findings

This section summarizes the findings from the case studies and from the semi-structured interviews. The analysis of the semi-structured interviews and the case studies revealed two overall findings: 1) a model for future planning and 2) barriers that interfere with parents starting and continuing a future plan.

4.3.1. Model of future planning

I have developed a model of future planning using data from the case study and semi-structured interview data. The two themes which inform this model are: 1) there are three categories of planning and 2) the process is temporal and ongoing. The model illustrates: the current status of future planning, what barriers might exist, where government policies can be changed or targeted, and possible areas where society or families can provide input. The goal of the model is a stable long-term future plan for the ADD.

1) THEME: Future planning can be categorized into three interconnected categories or areas of support: housing, services and supports, and financial/legal standing.

Future planning consists of three interrelated categories or elements: accommodation or housing, services and supports, and financial and legal structures. A visual diagram of the model can be seen below in Figure 2. Together, each of these components create a sustainable future plan for the ADD. One can visualize a future plan as a three-legged stool with financial planning, housing, and support each as a necessary leg. Without all three components, there is a strong possibility of a crisis situation precipitating when parents can no longer provide caregiving.
Financial and legal elements are the easiest to discern in future planning. The main purpose of legal and financial processes are managing the financial affairs and assets of the ADD.

Services and support processes are actions enhancing the ADD’s quality of life such as caregiving and community inclusions. The range and depth of services required varies according to the needs of the ADD. Support and services can be provided through professionals, paid supports, parents, family members, friends and the community where the ADD lives.

The housing or accommodation element is the physical place where the ADD lives. The housing process in future planning deals with the acquisition and maintenance of appropriate living accommodation. Unlike support, which can mix government-funded and family-supplied services, housing is either supplied by the government or supplied by the family. Which entity supplies the housing can change over the course of a future plan but the individual can only live at one location.

The model allows the actions or inputs that are associated with future planning to be categorized by purpose. An action may have more than one purpose. By carrying out the grouping, the overlaps between the elements become apparent; one strength of the model is the ability to demonstrate the relationships within future planning. Policy
changes that affect one of the elements can an impact on the whole of future planning. Models of future planning presented in other studies have allowed for inputs to be categorized. Other models have used the categories: financial, legal and housing (Joffres, 2002); financial/legal and living arrangements (Taggart et al., 2012); or listed five domains of future planning as residential, financial, legal, interaction with the service system, and companionship (Burke et al., 2012).

The following tables categorize the inputs that are associated with future planning in BC. The inputs come from the background review, semi-structured interviews and the case study for BC. The tables below are not a full list of inputs in the three elements of future planning but do provide a good starting point to qualify a future plan. The first table lists non-government actions in future planning and the second lists government actions.

**Table 3. Possible future plan inputs from individual, family, community and non-government funded organizations**

<table>
<thead>
<tr>
<th>Financial/Legal</th>
<th>Housing</th>
<th>Services &amp; Support</th>
</tr>
</thead>
<tbody>
<tr>
<td>Representation section 7 agreement from individual</td>
<td>House/condo</td>
<td>Representation section 7 agreement</td>
</tr>
<tr>
<td>Representation section 9 agreement from parents</td>
<td>Long term rental contract</td>
<td>Life-skills training</td>
</tr>
<tr>
<td>Will</td>
<td>Room-in with family or friends</td>
<td>Daily activities and inclusion</td>
</tr>
<tr>
<td>Discretionary trust</td>
<td>Special equipment</td>
<td>Privately paid and managed micro-boards and networks</td>
</tr>
<tr>
<td>RDSP</td>
<td>Community amenities</td>
<td>Informal support networks</td>
</tr>
<tr>
<td>Employment income</td>
<td>Transportation</td>
<td>Employment &amp; volunteering opportunities</td>
</tr>
<tr>
<td></td>
<td>Aging-in-place</td>
<td>Privately paid supports</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Advocacy by family and non-profits</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Holding the stories</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Close relationships (friends &amp; families)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Parental caregiving</td>
</tr>
</tbody>
</table>
Table 4. Possible future planning inputs from Federal government, Provincial government and government funded organizations

<table>
<thead>
<tr>
<th>Financial/Legal</th>
<th>Housing</th>
<th>Services &amp; Support</th>
</tr>
</thead>
<tbody>
<tr>
<td>PWD</td>
<td>CLBC funded accommodation (homeshare, group homes, and semi-independent)</td>
<td>CLBC funded programs</td>
</tr>
<tr>
<td>DTC eligibility</td>
<td>Non-profit owned accommodation</td>
<td>CLBC funded services</td>
</tr>
<tr>
<td>RDSP regulations</td>
<td>BC Housing subsidized housing</td>
<td>Health services</td>
</tr>
<tr>
<td>GIS &amp; OAS</td>
<td>HAFI</td>
<td>CLBC Facilitator</td>
</tr>
<tr>
<td>CPP</td>
<td>Transportation</td>
<td>STADD Navigator</td>
</tr>
<tr>
<td>Workshops and promotion on future planning</td>
<td>Specialized equipment</td>
<td>Life-skills training</td>
</tr>
<tr>
<td></td>
<td>Aging-in-place</td>
<td>Workshops and promotion on future planning</td>
</tr>
<tr>
<td></td>
<td>Subsidized rent programs</td>
<td>Advocacy by non-profits</td>
</tr>
</tbody>
</table>

2) THEME: Future planning is an ongoing process that takes effect as soon as it is started.

The term “future” can be misleading – future planning impacts the current situation of the parents and ADD. The plan is not futuristic; the bulk of a successful future plan is not launched when the parents die or are unable to provide care but occurs while the parents are still active in caregiving.

Future planning is a process taking place over years. This finding is in line with other studies that have maintained future planning is a process (Joffres, 2002; Heller & Caldwell, 2006). Future plans adjust to meet the goals and needs of the ADD and adjusts with available resources. Within the model of this study, no element of future planning is static in the long run. Financial planning changes as the RDSP becomes available for withdrawal and, again, when the individual turns 65. Housing planning can change if the ADD leaves the parental home, or changes residence, or changes the types of housing best suited to their needs. Support changes also happen as parents either slowly withdraw their informal services or if caregiving is abruptly stopped or
housing type changes. This means that getting a future plan in place sooner rather than later is helpful, as one parent stated:

“...what I would tell them is start early. Just like we did and I still don’t feel like we finished, it is a process.” (Parent interviews)

Evidence that future planning is a process is supported from the statements expressed by parents and non-profit employees in the semi-structured interview findings. Parents appear to be the most confident about their financial plans and the least confident about housing and support services. Services, especially in the form of the informal support network, have the least planning done.

Even though parents interviewed in this study had a future plan in place, they were still concerned about what the future might bring for their child. There were no guarantees for the future and they did not know if their plan would work. Parental confidence in the success of their future plans is shown by the two different viewpoints below.

“And you have to let go. I think that parents have to be up to let go and have confidence in the program.”(Parent interviews)

“A lot of us hope and pray, that our sons and daughters will pass away before us so they will not have to encounter all of our fears.”(Parent interviews)

As an added benefit, it was apparent that the future planning process had given the parents ‘their life back’. Listening to the parents talk about their lives, and comparing how they talk about their lives ‘before and after’ they had established elements such as financial planning, support network and housing, I perceived that they had less anxiety, they were able to reduce their level of caregiving and they felt they could take time for activities and vacations.
4.3.2. Future planning barriers

Barriers stop parents from starting the future planning process or stall progress in one of the three elements. Analysis of the semi-structured interviews reveals nine themes that can be barriers for parents carrying out future planning. These nine themes were selected because they had the most representation within an interview grouping (parents, non-profits, and government) or the most representation among all interview groupings. The general barrier associated with the process of future planning is:

1) Parents do not know how to start future planning

The element specific barriers are listed in Table 5 below:

<table>
<thead>
<tr>
<th>Financial/Legal</th>
<th>Housing</th>
<th>Services &amp; Support</th>
</tr>
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<tbody>
<tr>
<td>2) Legal issues surrounding representation and inheritance are not understood by parents and lawyers.</td>
<td>4) There is not enough housing that allows for aging-in-place.</td>
<td>6) Support networks require effort that is beyond the capabilities of most parents.</td>
</tr>
<tr>
<td>3) Families and ADDs do not have enough current income.</td>
<td>5) Lack of housing choice for ADD and family</td>
<td>7) Parents are worried about the future level of caregiving their child will receive.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>8) Parents are exhausted from providing caregiving.</td>
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<td></td>
<td></td>
<td>9) Parents do not know or understand the role of CLBC</td>
</tr>
</tbody>
</table>

1) Theme: Parents do not know where or how to begin future planning. In part, information is not reaching or being acted upon by parents.

Starting a new process or course of action is daunting. In many cases, families have been self-sufficient in providing the housing, financial support, and services for their child, but aging or illness necessitates they interact with a system that they have had minimal, if any, contact. Parents do not know how to overcome their fears and how to collect information. Uncomfortable decisions are often delayed or pushed aside until the issue becomes critical (Expert interview 1) as stated in the following quotes.

“It is panic based. Or it’s like ‘we don’t need to worry about that now’. I think it is fear-based. They do not know who they should talk to. For some
of them they have done it all on their own anyway and have done it well. They have not needed services. To go down that path is different for them.” (Non-profit interviews)

“So they were all living at home and the parents were getting older and the kids are getting older too. Either they didn’t know how to plan or they were sticking their heads in the sand and afraid to plan. There wasn’t any direction.” (Parent interviews)

Some parents may not realize the consequences or the impact on their child due to their inaction. In many cases, starting a future plan sooner would increase the quality of life for their child after the time when the parents cannot provide supports. If starting a future plan is delayed too long, there is a greater probability of forced decisions being made during a crisis situation.

2) Theme: Legal issues surrounding representation and inheritance are not understood by parents and lawyers.

Legal representation and estate planning need to be correctly executed for people with disabilities. Parents are unaware of the legal status of their child as an adult; some parents assume they have guardianship, but they cannot speak for their child unless their child gives them permission to do so. Representation agreements allow for others to make decisions for the ADD with their consent.

“A lot of times parents think that if I take care of my affairs, then my child will be taken care of. Under the law an adult child is independent, unless deemed by the court not to be. This is why I do representation agreement workshops. They don’t understand the importance of the section 9 and they don’t get a section 7 for their child. I’ve had many parents say “I’ve left instructions in my will about the Guardian for my child” but that no longer applies once their over 18. The lawyer should have corrected it.” (Non-profit interviews)

Estate planning and trusts can interfere with PWD and other government benefits if they violate income and asset tests for the benefits. Two non-profit employees stated lawyers did not always understand the implications of an inheritance directed towards a person with a disability. One parent had personal experiences with professionals who did not correctly write her will.
3) Theme: Families and ADDs do not have enough income

Most families and ADDs do not earn enough income to fund future planning. Currently, the incomes of ADDs are limited to low-paying work and PWD. The PWD is income and asset tested and, as a result, ADDs are kept at the poverty level. The low income makes it difficult for the ADD to live independently; ADDs do not have enough income to pay rent so they often live with family or roommates. Having a low income makes it difficult to save money for the future or afford fees for maintaining support networks through specialized organizations. The costs for services for ADDs are higher than most families can afford. The low income of the ADDs and the inability to pay for services by families are indicated in the following quotes.

“She lives on the poverty level anyway with basically what she earns. She’s capable of earning more but it’s kind of a catch 22.” (Parent interview)

P: “...are there very many people who can privately fund services?

P: They could, they would have to have some significant funding. The majority of the cost is the staffing. And you cannot pay babysitting rates.” (Non-profit interview)

4) Theme: There is not enough housing for people to age-in-place.

Parents, CLBC, and non-profit organizations acknowledge there is a lack of housing which allows ADD’s to age-in-place. The term “age-in-place” as defined by parents infers long-term housing. In the past, parents have struggled with long waitlists for government-funded accommodation and they do not feel confident their child will have a home in the future. From the interview analysis, it appears that all types of government-funded accommodation are in a state of under-supply.

P: “There are more people with developmental disabilities who want home sharing or that need a home share. We have a long waiting list of people who would like to be matched...

I: Home share is in short supply?

3 “I” indicates the researcher was speaking. “P” indicates the interview participant was speaking
P: Absolutely.
I: Ok as I suppose are all the other types of residences?
P: Oh yes, more so, more so because CLBC from a cost perspective, a financial perspective to the province, it’s much more economical for them to place an individual in a home share than it is in a fully staffed home.”(Non-profit interview)

The issue of adequate housing is critical to the quality of life for ADDs for several reasons: to prevent inappropriate placements in long-term care homes; to avoid emotionally upsetting the ADD with multiple moves; to allow for greater community inclusion; and to create long-term relationships that can discern medical and aging changes in the person.

“The other thing about continuity in housing, is you have people that hold your story. Not somebody new who did not know who you were before. It is very difficult to assess the critical issues that are emerging with aging when nobody knew who you were when you were doing better.”(Government interview)

Housing must be safe for people and take into consideration the aging stages of the ADD. Stairs, bathroom layouts, and location are examples of features that can pose hazards in government-funded home shares and in parent-supplied houses. Even parent-supplied housing may not guarantee a place to live if government-funded services are not provided.

“A lot of older parents do take that approach. They say “I have saved all my life, the house is paid for and I want my son to live here and they’re not moving”. I have to get them to realize, diplomatically, that it does not guarantee services will come to that house. If they die tomorrow, their son or daughter would be in the house without supports.”(Non-profit interviews)

5) Theme: Lack of housing choice for ADD and family

Parents and non-profits acknowledge housing choices are limited if the ADD is to leave the family home. Both parents and non-profits feel, regardless of the individual’s needs, that CLBC wants to place everyone in home share.

“…home share is the label. What home share is and what a home share looks like all depends on the person. Each and every home share is
unique and individual. We really do need to qualify what a home share is. It can look like anything that the person who is requiring home support needs. It can look like your typical family. It's the 24/7 support. Or it might look like a single person and the other person moving in, more like a companionship. Or it can look like husband-and-wife or it can look like whatever the person needs. It's all about the matching." (Non-profit interview)

While home share can take on many forms, parents are most familiar with the foster family model and do not feel this form is a good fit for their child. Home share is closely associated with government cost-cutting measures and parents have concerns whether the home share family is able to support their child’s social life and behavior.

“Home share has become very popular because it is a less expensive model. And from what I've heard from some of the service providers they are being told it is the only model.” (Non-profit interview)

“All you get is: living with family, living in a group home which they are closing anyway, and the big one is home share, adult foster care.” (Parent interview)

The parents who were interviewed stated they wanted choice for their child’s housing and these parents, or in one case the ADD, had a concept of the ideal residency. The parents advocated and pushed to get government-funded accommodation that fit their child or, in one case, the parents supplied private accommodation.

6) Theme: Service support networks require effort that is beyond the capabilities of most parents.

Service support networks should ideally last for the lifetime of the ADD but the creation and management of support network is beyond the capabilities most parents. The purpose of support networks is to provide services and decision-making past the time when parents are no longer able to carry out these duties. An informal support network consists of friends, family members and acquaintances who know the ADD and will be able to provide services over the long-term. The long-term commitment makes it difficult for parents to ask family and friends.
“That is one of the greatest hurdles of the network. It’s a simple concept but actually finding people is not that easy. So what they do is look into your own network, your family and friends, and see if there’s something that could work. Most of the people that we have in our network are from our own connections.” (Parent interviews)

Support networks are similar to managing a company. As individuals leave the support network, other individuals need to be recruited in order to keep the support network running over the lifetime of the ADD. Someone must take on the role of facilitating action from the other members on the support network in order to support the ADD. Setting up the structure and recruiting the right people needed for longevity and quality output is challenging.

“They really work for some families. They don’t work for all families because they are a lot of work. A micro board is a board of directors. You have to be prepared to take that on full stop. The financial stuff, the human resources, the training, all of it. Some people have the capacity and skills. As much as people say they like what micro boards give them, they are exhausted because they are always running the board.” (Government interviews)

In addition to the informal network, the formal support network, whose members are government paid support and professionals, are also part of supports the ADD will receive in the future. The formal support group members may not be aware of others, whether they are part of the informal support network or other professionals. Likewise, informal support groups may spend too much time navigating the system because they do not have members from CLBC or the health system.

“They are already sort of the integrated support network, but they may all be operating in silos from each other and working towards the same thing.” (Government interviews)

7) Theme: Parents are worried about the level of caregiving their child will receive.

Parents are concerned that the future level of caregiving their child receives will not be the same quality that the ADD’s are currently receiving or meet their needs as they age. Parents are uncertain about the informal caregiving and the formal paid services. Parents provide large amounts of informal caregiving and, implicit in their caregiving, is caring social interaction with their child and advocacy. Parents feel no one
will fill this role when they are gone. Government-funded caregiving is a concern to parents because they cannot control the future quality or quantity given to their child. The long waitlists do not give parents any confidence that government services will be there for their child. Governments do not guarantee their services in their current form.

“I think we all agree that it is very scary to think how they will be looked after, after we are gone. Will other people care for them, obviously not as much as we do, but will they care for them enough?” (Parent interview)

“The government has always delivered services. I don’t think the services will disappear. I think we have to re-imagine what those services will look like. And ask community to take more responsibility. We’ve done a brilliant job of getting in the middle, such that community does not feel that they have a responsibility.” (Government interview)

8) Theme: Parents are exhausted from providing caregiving.

Caregiving for an adult with developmental disabilities can be physically and emotionally demanding. Parents may not have the time or the energy to start or maintain a future plan. Parental aging can increase the feeling of exhaustion and, as a result, parents either do not start or do not continue future planning. Their ability to collect information, advocate for their child, start the RDSP, and create a social network with others can be compromised. Incomplete or nonexistent future plans result in a higher number of decisions made in a crisis situation and can result in a less suitable outcome for the ADD.

“The other thing is, you have to think what families are going out and being vocal and advocating for their loved ones. These are the families that have the energy, financial ability, education. I would like to know what families are out there that have all of this because, you’ve got to understand, some the families out there, they don’t have the energy to do this. You think of Maslow⁴, they are just trying to get their basic needs met. They don’t have the energy or the support to do all this.” (Non-profit interviews)

“Having a child with a developmental disability can be exhausting. At the end of the day you are tired and the thought of doing something more,

⁴ Maslow’s hierarchy of needs
you just don’t want to do it. “Do I have to do that”? So I think there’s that reluctance”. (Parent interviews)

9) Theme: Parents are unaware of the role of CLBC. Parents either do not know of the services CLBC provides or over-estimate the resources of CLBC.

Non-profit organizations and CLBC are concerned that parents do not understand the role of CLBC. According to these agencies, parents generally fall into two camps: parents are unaware of CLBC’s existence and what supports CLBC offers or parents do not realize that CLBC is not required to provide supports. Some parents have provided care to their child without any government-funded assistance. While services to ADDs under the age of 19 are mandated, services to adults are optional and fulfillment of requests are not guaranteed.

“One of the key things for families to understand is the shift from childhood to adulthood and that adult services are not legislatively mandated, so there isn’t a mandated requirement that somebody receives services through the provincial government.” (Non-profit interviews)

“We have to deepen the understanding of community about what the resources of CLBC are. It is still concerning how many families don’t fully understand what CLBC does. As a consequence, they cannot avail themselves of the resources, information, or access resources because they don’t know what is out there. Some families, particularly that are aging, have never touched the system because they have never asked for help.” (Government Interviews)

As a consequence of the lack of knowledge about CLBC, crisis situations can occur when the parents can no longer provide caregiving. For the situations where the family has not previously registered an individual plan, CLBC cannot plan or budget for services if the ADD is not registered with the agency. Eligibility for CLBC services must be established for the ADD before long-term services can be accessed. However, being registered with CLBC does not mean the services will be readily available or will meet the entire support needs of the ADD. The consensus is that parents need to plan for non-government support in the future.
4.3.3. **Findings Conclusion**

The findings provide the key points for future planning in BC. While both research questions were examined in the semi-structured interviews and the case studies, the outcomes of each, for the most part, informed one question better than the other. Semi-structured interviews informed the nature of the barriers, while case studies presented possible policy options. The findings meshed together to provide valid options for BC.
Chapter 5.

Policy options

The policy options presented in this section are directed at BC government actions that can encourage parents to complete a future plan. Provincial government action is warranted for two reasons: 1) government action improving future planning has been successful in the past as shown by the federal RDSP and the provincial representation agreement and 2) government action has a whole-province scope. The options address the findings presented in section 4; the semi-structured interviews identified the barriers and the case studies identified the possible responses to the barriers. The status quo was not considered an option, but is used as the benchmark by which to judge other options. I present the follow four options:

1) Information campaign to improve and strengthen the information on future planning available to parents.
2) Increase the choice of housing for age-in-place. Open a grant process similar to the EPCIT to allow for a variety of housing options.
3) Create a role based on the STADD navigator that will facilitate the creation of support networks.
4) Increase respite for parents or caregivers over the age of 50 with tie in with future planning sessions.
5.1. Information campaign

Option: Information campaign to improve the availability of future planning information to parents using a variety of channels.

A government-led information campaign addresses the lack of information and the misinformation that was the subject of three themes. As stated in the findings, Theme 2, parents are often poorly informed about guardianship and the how inheritances may affect the ADD’s government incomes. Information on legal representation and estate planning can improve the number of ADDs with a representation agreement and reduce the number of wills that may violate government benefit regulations. Parents require information on the types of services the government and CLBC provides, as shown in Table 4, and they need to know the limitations of those services. Finally, if parents are given instructions on how to start planning their child’s future, there is a higher probability they will act. Searching for information, evaluating sources, and comparing alternatives take time; an information campaign presents parents with these initial steps completed.

Information campaigns, utilizing a wide variety of methods, have been successful in encouraging socially-desirable changes in behavior (Howlett, Craft, & Zibrik, 2010) and have been used in other jurisdictions to encourage future planning (Heller &
Caldwell, 2006). The “Future is Now” is a series of workshops on increasing non-parental services; accommodation issues; retirement and leisure; legal and financial planning; and identifying a key succession person. The program was evaluated by Heller and Caldwell (2009) who found the majority of families took action on planning housing and a letter of intent. In Canada, information campaigns have been used by Elections Canada to bring out the vote (Howlett et al., 2010). In Australia, a health service area initiated a campaign to encourage on pneumococcal immunization in people over 65 years and saw a 33% increase during and immediately following the television advertisements (Wallace, Corben, Turahui, & Gilmour, 2008).

An information campaign would build on the success of the previous workshops by using the same platform but increasing the number of events, utilizing more types of media and covering all the elements in future planning. Utilizing multiple channels to spread information increases the probability that families will have some familiarity with future planning and start planning. In addition, parents and the ADD interact with a range of people from government employees, family, other parents, banks, lawyers/notaries and service providers, each of whom can facilitate the future planning process if they too are informed and educated. An information campaign can also promote CLBC’s definitions of future planning for the purpose of having consistency in planning.

“By the nature that we do business, we contract many thousands of agencies and they are going to use their own spin on what they think a financial plan should be, what a support network is. However if they turn to CLBC resources, there is a clear definition of what that is.” (Government interviews)

Different modes of information may appeal to different generations or different social economic groups. Care must be taken in designing information campaigns so that inequities of accessing information are not increased (Baxter & Glendinning, 2011). The age of the target audience is a determinant of successful media types (Godin, Dujardin, Fraeyman, & Val Hal, 2010). Non-profits reported that parents in their 80s preferred several face-to-face meetings to discuss planning for the future (Non-profit interviews). Younger parents may feel comfortable doing Internet research (Expert interview 1). More research is needed to find out whether the popularity of workshops is specific to the generation of parents that I interviewed.
Websites are often the first point of contact with government agencies by those seeking initial information on programs, services, and benefits. Future planning could be encouraged by having a stand-alone website similar to the one developed by The Arc, a US-wide non-profit organization dedicated to advocating and serving people with developmental disabilities. The Arc’s website, Center for Future Planning (please see figure 3) (ARC, n.d.), could serve as model for this option with information and links to non-profit agencies specializing in future planning, RDSP (Revenue Canada), NIDUS, and CLBC. By having a stand-alone site, planning information will not be pushed aside by other policies or events.

**Figure 3. Center for Future Planning - The Arc website**
5.2. Implement housing grants

Option: Increase the choice of housing for aging-in-place. Open a grant process similar to the EPCIT to allow for a variety of housing options.

Housing is a critical element in future planning and parents need to be informed about possible housing options in order to undertake future planning (Taggart et al., 2012). The barriers in the housing element of future planning are addressed in this option. The three barriers as revealed in the findings are: 1) lack of housing for aging-in-place, 2) a lack of housing choices and 3) families lack financial resources to pay for housing.

Parents, non-profits and government agree that the current government-funded accommodation stock is not large enough and many places are not suitable to age-in-place. Whether an accommodation is suited to aging-in-place, depends on the built environment. A study of the value of home modifications in England revealed that modifications and housing type increased the length of time older people stayed in their homes (Hwang, Cummings, Sixsmith, & Sixsmith, 2011). In addition to the importance of the physical layout inside the house, the physical neighbourhood amenities outside the house also contribute to aging-in-place (Sixsmith & Sixsmith, 2008).
Currently, CLBC is promoting home share and withdrawing from funding group home beds. Home share does take many forms as listed in the findings (Theme 5: Lack of housing choice for ADD and family) but parents do not perceive the different forms of home share as different choices. The parents who were interviewed expressed their frustration with the lack of accommodation choice and lack of long-term housing offered to their child.

“Because the concept that we had, along with the community aspect, is the kids could age-in-place and that they wouldn’t be shuffled around. The governments, what they offer in terms of home, home share or group homes, this would not work for these kids.” (Parent interviews)

A government-funded program similar to the EPCIT in Queensland (see section 3.2.6 or Appendix K) would expand accommodation choices and increase the number of places suitable for older adults. EPCIT was developed to search for innovative housing choices for adults who are currently living with elderly parents. EPCIT is a trial but the BC government could adapt the EPCIT program to include physical features that would facilitate aging-in-place. Innovation from the non-government sector has been cultivated through the rules of EPCIT and through the open proposal process which increases the transparency of awarding the grants. In this option, the government grants supplement the organization’s capital input and the grants are tied to the long-term commitment of providing accommodation for the eligible population. Like the EPCIT, the maximum grant amount should be capped and organizations will need to provide the bulk of the capital funding and cover maintenance costs. Successful proposals fulfill the gaps indicated by the two barriers: 1) the proposals, by virtue of fulfilling the rules of an EPCIT-similar program, create new housing capacity and 2) expand the choice of accommodation. Additionally, this policy option complies with Article 19 of the UN Convention of Rights of Person with Disabilities.
5.3. Create a role for supporting networks

Option: Expand the STADD navigator role across the province to enhance support networks.

The navigator option reduces the barriers in support planning. Expanding or adapting the navigator role addresses: 1) parents who do not know where to start, 2) the uncertainty surrounding future caregiving, 3) starting and maintaining support networks, and 4) families cannot afford privately-paid network managers. Families who do not know where to start can be referred by a service provider or self-refer to a navigator who will start the planning process.

In this option a navigator would help parents start the planning process, set up an integrated support network, and help parents identify a key person(s) for their future plans. Baxter & Glendinning (2011) refers to a similar role to help disabled and elderly adults with navigating the healthcare system as a “specialist information advocate” (Baxter & Glendinning, 2011, p. 278). A key person who would direct future services for the ADD has been supported in the literature (Ryan, et al., 2012). The navigator helps
parents to set up a future plan by providing information and, once the plan and the integrated support network are in place, the navigator can assist the key person(s) as required.

The strength of a navigator role is bringing together everyone to the ‘table’ and establishing an integrated support network, a network which include both informal and formal support networks. An informal support network is composed of family members, friends and neighbours who help care for or make decisions for the ADD. Informal networks may also be called “circles of support” (Taggart et al., 2012). Parents and informal networks do not have the ability to include the formal networks of CLBC and the Ministry of Health personnel. Having the government-funded agencies and professionals along with the informal network working together, increases the scope of actions that can be incorporated into a support plan and makes the future plan a known entity. The limitations of government-funded services can be acknowledged in the future plan. Through the meetings with the navigator and the integrated support network, parents will have a reasonable understanding of the supports their child will be receiving.

The concept of a social worker, navigator or team to work with parents to develop future plans has been proposed in other studies (Taggart et al., 2012) and is already being done on a private-funded basis by non-profit groups such as PLAN (Joffres, 2002). However, the cost for private funding a navigator may be unaffordable for many families. In one US paper, the use of government-funded social workers to support families with individualized care plans was proposed (Parish & Lutwick, 2005). As described in Case Studies in section 3.2.3, the navigator role occurs within the STADD prototype currently being tested in Burnaby. One of the functions of the navigator is to assist ADDs with all planning. In order to facilitate future planning in the province, either a new position similar to a navigator needs to be created or the current role of the navigator requires the following adjustments: reduce the starting age of eligibility for the program from 55 years, focus on future planning, and expand the number of navigators throughout the province. From a government perspective, registering ADDs who are not known to the formal care system is important to future planning (Ryan et al., 2012) and a government navigator role can ensure the registration of ADDs.
The navigators in the STADD prototype establish a common understanding of what the needs of the ADD are with the integrated support network. After discussions with the ADD and receiving consent, the navigator starts the support planning process by convening a meeting with both informal and formal support networks.

"Convene an integrated support meeting. It could be family, friends, service provider possibly, and the key partners like health and CLBC, maybe the PGT, and have the conversation. So everybody knows what’s going on, that is the piece. The individual is identified". (Government interviews)

The navigator also provides follow up:

"So we come out of the meeting with a sense of a team approach to supporting the plan. From there I would move more into the role of managing the plan. Which is following up with people: “so how did it go? You said you’re going to do this”, “oh there has been a change”. So if there’s been a change, than we can adjust our strategy.”(Government interviews)

The work provided by the navigator significantly reduces the efforts required of the parents in future planning. The navigator will increase the number of families with a support network, especially families without resources or education.
5.4. Tie increased respite to future planning

Option 4: Increase respite for parents or caregivers over the age of 50 with a tie-in to future planning sessions

The respite proposed in this option is in addition to the respite currently received by aging parents or the respite required by the family to continue caregiving. Respite allows carers, who live with an ADD, a break from caregiving (Weeks et al., 2009) or allows them to recover from physical ailments. Respite can take forms such as day programs for the ADD (Ryan et al., 2012), in-home, short-term stays and longer-term care (Lund, et al., 2014). Parents may not have the funds to privately purchase respite (Ryan et al., 2012), so government funding would be required. This policy option considers the scenario where parents do not have the time and energy to plan for the future. As stated in the findings and literature review, aging parents find caregiving requires considerable effort, mentally and physically. The time and effort drains parental motivation to start or maintain a future plan.

A modified respite program, similar to the Older Carer Initiative in the Queensland Case study, would provide a break for aging parents and offer parents the opportunity to start future planning. In the Older Carer Initiative, families who are receiving respite can meet with project officers to discuss the support needs and future housing options. Similarly, in this option, I propose that extra respite be provided to carers 50 years and older with the proviso the parents attend workshops on future planning or engage in some task related to future planning. The age of 50 was chosen to allow families time to utilize the advantages in RDSPs.
Directing some of the parent’s respite time to future planning is key, but caregivers may need outside direction and help in planning the best use of their time (Lund, et al., 2014). An intervention called Time for Living and Caring found caregivers were more satisfied with their respite time when a facilitator helped them to set goals that they worked on during their break from caregiving (Lund, et al., 2014). The link between future planning and respite is shown in the following quote:

“Offer some respite support and get some safety short-term plan. Then have a conversation about long-term. Planning is the key. Educating people to make those endeavors to plan.” (Non-profit interviews)
Chapter 6.

Criteria and measures

This section describes the criteria and measures that I will use to evaluate policy options. The criteria chosen appeared to have the best fit with the goal of expanding and enhancing the current state of future planning in BC. The criteria are:

- Equality of opportunity - Is it fair?
- Capacity - Is there room?
- Effectiveness - Does it tackle the problem?
- Stakeholder acceptance - Would it be desirable?

The criteria are presented in Table 7.

The criteria evaluate the “concept” validity of the option. Cost is not considered as criteria for the following reasons:

- Without a strong grounding in validity, an option will not accomplish the action to address the problem, however when cost is a criteria it could swing the evaluation in such a way that an invalid option can win. A cheap option is not the best.
- Costs for government programs, government offices and government employees are not available to the public. However, cost can be considered as part of the government stakeholder acceptance.

The statistics do not exist for benchmarking or evaluating impacts of policy options and, instead, a general scale is used to estimate the impact or value of enacting a policy. For evaluating effectiveness and stakeholder acceptability, the status quo, as presented in the background and BC case study, was used as a benchmark. The defined scale used by each criteria is:
### Table 6. Defined scale for measuring criteria

<table>
<thead>
<tr>
<th>Less than status quo or negative impact</th>
<th>Same as Status Quo or no impact</th>
<th>Slightly better/improved than status quo or minor positive impact</th>
<th>Better than status quo or medium positive impact</th>
<th>Much better than status quo or high positive impact</th>
</tr>
</thead>
<tbody>
<tr>
<td>-1</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>

### Table 7. Criteria and measures

<table>
<thead>
<tr>
<th>Criteria</th>
<th>Definition</th>
<th>Measure</th>
<th>Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Equality of Opportunity</td>
<td>Degree to which the policy option is accessible to families with a person with a disability.</td>
<td>An estimation of the level of opportunity that families have to partake in the option across the province and across social economic classes</td>
<td>A combined percentage of 50% for reaching eligible families across the province and 50% for across social economic classes. Using the defined scale in Table 6.</td>
</tr>
<tr>
<td>Capacity</td>
<td>The volume of families that the policy can accommodate and provide positive impacts, should the family want to participate.</td>
<td>The estimated level of number of families that the policy can assist, over five years of the number of families</td>
<td>A level using the defined scale in Table 6</td>
</tr>
<tr>
<td>Effectiveness</td>
<td>The degree to which the policy, if offered, will make a difference in a family’s action to 1) start a future plan or 2) improving existing future plans</td>
<td>A comparison to the status quo. The increase of families who 1) start a future plan and 2) improve their plan</td>
<td>A joint probability where new families with a future plan are weighted at 75% and families with a future plan before the policy is implemented weighted at 25%.</td>
</tr>
<tr>
<td>Stakeholder Acceptability</td>
<td>The degree to which the policy option is accepted and/or put into practice by the stakeholders</td>
<td>A comparison to the status quo. The estimated probability of acceptance by: 1. Families (parents and ADDs) 2. BC government and crown agencies 3. Non-profit organizations</td>
<td>Joint probability = 1/2(family) + 1/4(government) +1/4 (non-profit) Using defined scale in Table 6</td>
</tr>
</tbody>
</table>
6.1. Equality of opportunity

Equality of opportunity judges whether the policy option is accessible to all parents providing care to an adult child with developmental disabilities. Accessibility is estimated on two different fronts: 1) whether the option is available across the province and 2) whether the option is open to all families regardless of social economic status.

Equality of opportunity can also be characterized as substantive equality (Barnard & Hepple, 2000). In this view, equality is attained when the barriers to participation are removed and when the goal is to achieve equal outcomes for vulnerable groups as compared to non-disadvantaged groups (Barnard & Hepple, 2000). Social factors and the geographical location where ADDs and their families live are acknowledged by the participants in the semi-structured interviews as influences on future planning. Rural areas and persons with lower social-economic backgrounds face barriers to equal access. The impact of lack of equality has been established in studies that have looked at the relationship between health outcomes and social factors; those who have a higher social economic status or live in urban areas have a greater ability to access healthcare leading to better outcomes (Bekalu, 2014). The formula for the total value is: 50% (accessibility across the province) + 50% (accessibility across socioeconomic status).

6.2. Capacity

In performance evaluations of social programs, capacity can be viewed as throughput, a measurement of productivity (Packard, 2010). Capacity can be limited by the structure of the program as defined by the processes dictating the delivery of the program, including staff performance (Sowa, Coleman Selden, & Sandfort, 2004). Additionally, I would add capacity is affected by the resources allocated to the program. Since social programs are delivered by government agencies or through government funding of non-profit organizations, capacity is an important issue for all stakeholders.

Capacity, in this paper, is defined as the number of families the policy can accommodate at over a five year period. Capacity of a policy option is measured by its
exclusivity; the question is: how many families can be served before the limits of process or resources is reached during the given period? Given the target population, those who wish to participate and are given access to the policy option are provided with a positive impact on their future planning. The flip-side, those who want to access the policy but cannot because the option is full are denied the service/opportunity and will not be made better-off. These families will be on a waitlist.

6.3. Effectiveness

Effectiveness is the third criteria and is defined as the degree to which an option, if offered and available, would cause the desired effect. Many definitions of effectiveness exist for social programs and, for this paper, effectiveness is defined as achievement of desired client outcomes (Packard, 2010). Effectiveness is defined as a family’s response to the policy and answers the question: would offering a family the option successfully encourage a family to act on future planning? Effectiveness is the quality of the policy and is assigned a double strength, for without the outcome of encouraging future planning, the option does not address the policy problem.

The starting point for measuring effectiveness is the comparison of the proposed option to similar current programs in place to encourage future planning in BC. Two groups within the population are examined: the effect on a family that has not started any planning and the effect on a family that should improve their future plan to cover all the elements. The formula for effectiveness measurement is: 75%(new families) + 25%(families with improved plans).

6.4. Stakeholder acceptability

Stakeholder acceptance, as a criteria, acknowledges that the perception of a policy option varies between different affected groups; how different groups accept the option and judge its performance is socially constructed (Packard, 2010). Evaluating acceptance involving stakeholders need to consider the values, information and resources held by the each group (Sibbald, Singer, Upshur, & Martin, 2009). Families,
defined as both the parents and the ADD, are the targeted population for the policy options that encourage future planning and as such are the most important group of the stakeholders. The voices of both the parents and the ADDs are combined to make the viewpoint of the family. It should be noted ADDs were not interviewed in this study and the viewpoints of ADDs in other studies are from limited samples (Salvatori et al., 2003). Families, non-profit organizations and government are different groups, each with a position in future planning: families make the decisions in future plans, non-profits are the liaisons that provide resources, and the government provides funding and regulations. I acknowledge that the populations within each of the three groups are not homogenous but I present an overall view for each group given the findings from the analysis.

Another way to view stakeholder acceptance is as a residual; the option captures factors that will not be captured in the evaluation using the other criteria. By weighing their costs and benefits as an aggregate, the position that each group expresses holds all factors. Each group considers whether the policy option is an improvement from the status quo given any new costs, monetary and non-monetary, incurred by the option.
Chapter 7.

Evaluating the policy options

The policy options are scored below in Table 8 using the criteria and measures found in Table 7. The numbers are determined from applying the ‘Value’ column of Table 7 to the evaluation of the policy option for each criteria. As per Table 6, the range of possible valuations is ‘-1’ to ‘3’, where ‘3’ indicates the best score and ‘-1’ indicates a very poor score.

Table 8. Scores for the policy options

<table>
<thead>
<tr>
<th>Equality of Opportunity</th>
<th>Information campaign</th>
<th>Increase the choice of housing</th>
<th>Expand the STADD navigator role</th>
<th>Increase respite for parents</th>
</tr>
</thead>
<tbody>
<tr>
<td>2</td>
<td>1.5</td>
<td>2.5</td>
<td>2.5</td>
<td></td>
</tr>
<tr>
<td>Capacity</td>
<td>3</td>
<td>1</td>
<td>1</td>
<td>1.5</td>
</tr>
<tr>
<td>Effectiveness x 2</td>
<td>(1.5)</td>
<td>(2)</td>
<td>(3)</td>
<td>(1.75)</td>
</tr>
<tr>
<td></td>
<td>3</td>
<td>4</td>
<td>6</td>
<td>3.5</td>
</tr>
<tr>
<td>Stakeholder acceptance</td>
<td>2</td>
<td>2.25</td>
<td>2</td>
<td>1.5</td>
</tr>
<tr>
<td>Totals</td>
<td>10</td>
<td>8.75</td>
<td>11.5</td>
<td>9</td>
</tr>
</tbody>
</table>
7.1. Information campaign evaluation

Equality of Opportunity:

Province wide: 2 (50%), social economic class: 2 (50%), Total score: 2

An information campaign reaches everyone who has the access to the means or mode of the information transfer. Information travels freely through the internet; workshops and forums are open to all; and brochures can be mailed or left for voluntary perusal at community centres, doctor’s offices and libraries. Information campaigns can cover large geographical areas including entire countries (Howlett et al., 2010; Wallace et al., 2008). However, workshops are usually confined to smaller geographical areas where there is larger populations. When information campaigns use the appropriate media channels, all social economic groups can receive the information. As an example, in Canada Elections Canada has used information campaigns to target unrepresented groups such as Aboriginal voters and youth (Howlett et al., 2010).

Internet as a media channel does challenge the criteria of equality of opportunity. An examination of digital divide questions whether an information campaign using the internet as a component is accessible to aging families with an ADD. Two opposing arguments shed light on accessibility. The gerontology expert stated that seniors have become more comfortable using the internet and using the internet has made it easier to plan (Expert interview 1). However, while the rates may be increasing for those over 55 years, a study using the 2010 Canadian Internet Use Survey found only 56% of individuals over the age of 55 years accessed the internet in the past year (Haight, Quan-Haase, & Corbett, 2014). Rural residents and families with annual incomes under $25,000 also have lower access to the internet (Haight et al., 2014). Those who use the internet are more likely to be urban, better educated and have higher incomes. The reliance on internet to disperse information on future planning may not be an equitable approach, as it may further widen the social economic gap (Bekalu, 2014).
**Capacity:**

*Total score: 3*

Information campaigns have the ability to serve everyone, even in countries with large populations (Howlett et al., 2010; Godin et al., 2010). The internet has unlimited capacity and can display the same information over years. While printed material is limited by its distribution and workshops may be limited by number of seats, information from these media types is not bound to those who have participated. Many older adults share information that they have been exposed to with friends and acquaintances (Godin et al., 2010) and, as a result, the capacity of information campaigns is increased by spreading the information within the older cohort of parents.

**Effectiveness:**

*New families: 1.5 (75%), Families with a plan: 1.5 (25%) Total score: 1.5*

The effectiveness of information campaigns is not easily measured in the short term for social programs. Yet, without information on housing, services, and financial/legal matters parents cannot plan for the future. Gathering information is a precondition to choice; people need information to know about availability of services before making decisions (Baxter & Glendinning, 2011).

The effectiveness of an information campaign to encourage parents to plan for the future depends on the design of the campaign. Providing parents with information raises the probability of action but information is also easily ignored or not recalled (Godin et al., 2010). While TV spots and posters were effective in encouraging immunizations in Australia (Wallace et al., 2008), as the length of time from the campaign increases, recall of the campaign drops (Godin et al., 2010). Compared to the status quo where information has been disseminated through workshops, internet webpages, brochures and printed material, an information campaign may not be significantly more effective if implemented. Even if aging parents do have access to the internet, the findings from the semi-structured parent interviews showed parents do not use the internet to research issues related to their child.
“However, I’m on the internet all day looking up stuff but usually not to do with her” (Parent interviews).

Another common view of information on the internet is the overwhelming amount of information and the inability of the reader to distinguish helpful information from other information (Baxter & Glendinning, 2011).

**Stakeholder acceptance:**

*Families: 2 (50%), Government: 2 (25%), Non-profits: 2 (25%), Total score: 2*

Evaluating stakeholder acceptance is drawn from the findings of this paper, findings of other studies and the actions stakeholders are currently taking or will be taking in the near future.

Parents would be accepting of information campaigns. In the semi-structured interviews, parents spoke of attending workshops, seeing articles in newspapers and hearing information from acquaintances that they feel should be recommended to other parents with an ADD. Satisfaction with information campaigns increases with age (Godin et al., 2010).

ADDs would benefit from an information campaign if the campaign was set up to include them. Heller and Caldwell (2006) found that ADDs who attended adapted workshops for *The Future is Now* communicated their desires for the future and this leads to increased self-determination. Salvatori et al. (2009) suggests ADDs are not drawn to conceptualizing the future except when it can be closely related to their daily life. The design of the information campaign would need to facilitate ADD involvement.

The actions of non-profit organizations and government indicate acceptance would be ranked as good. Non-profits organizations and CLBC are currently using workshops and brochures supplemented with minor internet presence to provide parents with information about future planning. CLBC has promoted its Strategy in Aging with forums, brochures, and webpage. CLBC, STADD and PLAN are each working on additional internet information which will be on-line in the near future (Government interviews, Non-profit interviews).
Non-profits often host the workshops which usually provide information on financial and legal planning that parents find useful:

“We have gone to several workshops. PLAN has put on workshops and we have gone to a series that they put on, on wills and estates, finances and housing. PosAbilities also, combined with BACI, put on workshops a couple of years ago covering all of the same things.” (Parent interviews)

7.2. Evaluating increasing housing through grants

Equality of opportunity:

Province wide: 1 (50%), Socioeconomic: 2 (50%), Total score: 1.5

Accessibility to a housing program is limited by location but is unlikely to be limited by socio-economic status. Increasing the choice, and therefore the number of accommodation units, will make housing more accessible to people who may be disadvantaged and do not have the option to provide their own housing suitable to age-in-place as illustrated in the following quote.

“We feel that at this point we’ve done everything that we can have up to this point. Our next stage is what is going to happen? …If we die, we’re not really convinced that he can stay in his own place. Then what, then what’s next? There’s not a lot out there. We can’t afford to put him into an assisted living place with seniors. So we have to choose something that we can get some help with and that’s quite a limited choice. So there’s a lot of uncertainty around that.” (Parent interviews)

Since the organizations that apply for the program need to provide the bulk of the capital costs, organizations located in areas with a smaller population or lower economic status may not be able to apply for the grant. Areas that are rural or northern may not have the ability to raise funds to create housing (National Advisory Council on Aging, 2004; SDSI, 2014).
**Capacity:**

*Score: 1*

Housing is a physical element and does have a property of exclusivity. When an accommodation unit is occupied, others cannot participate in the benefits of that unit. The creation of new units and choice may free up other units and increase the capacity of the current housing situation but eventually the limit of housing units will be reached.

**Effectiveness:**

*New families: 2.0 (75%), Families with a plan: 2.0 (25%) Total score: 2.0*

The findings from the semi-structured interviews indicate that obtaining suitable accommodation for their child was critical to the progress of their future plan. For those who have started a future plan, the choice in housing may allow them to further expand their plan. Weeks et al. (2009) study of Prince Edward Island families indicated parents would welcome a wide range of housing choice including options where the family was kept together to age-in-place, and this would be beneficial to planning for the future.

However, from the literature review and non-profit interviews, it was determined that not all families want the ADD to leave the family home. Taggert et al.’s (2012) study in Northern Ireland found over 80% of carers wanted the ADD to stay in the family home. Two non-profit employees related stories about families who wanted the ADD to remain in the family home.

“A lot of older parents do take that approach. They say “I have saved all my life, the house is paid for and I want my son to live here and they’re not moving”. (Non-profit interviews)

For these families, increasing housing choice would not encourage future planning progress.

Aging-in-place or longevity of residency for ADDs depends on the physical environment both inside and outside the home (Sixsmith & Sixsmith, 2008). Additionally, the ability of an ADD to age-in-place would depend on the in-
home services provided (Sixsmith & Sixsmith, 2008). If the grant option resulted in housing allowing for aging-in-place, this option would be effective.

**Stakeholder acceptability:**

*Families: 3, Government: 1, Non-profits: 2, Total score: 2.25*

All stakeholders acknowledge the current housing situation is lacking suitable spaces to age in place. However, different viewpoints of suitable accommodation for ADDs pits inclusion against opening choice to include other forms of housing.

Parents want choice in housing beyond home share as indicated in the findings, Theme 5. To further the housing choices, some parents have tried to create alternatives to the current offerings:

“The architect came on board and drew it [a multiple-unit accommodation for ADDs] up but it [plan for accommodation] never went anywhere because the government looked on it as an institution. But my goodness, we have these people living in assisted living that have their own apartments yet they get assistance with medications and eating and dressing. They all eat in a common dining room. I don’t see the difference. How come it’s okay for them but not okay for our daughter?” (Parent interviews).

ADDs often thrive when their housing situation is a “fit” for their needs. A 2010 study of housing choice in Australia provides findings implicit to future planning (Fisher & Purcal, 2010). Examining the findings of the study by Fisher and Purcal, explicitly related to individuals who had previously lived with their parents, revealed that with housing choice, social networks were maintained and life skills were enhanced. Overall:

“In conclusion, personalized approaches to disability housing supports are effective compared to group home support and to living with family, when outcomes are defined from the perspective of the clients’ experiences. Client outcomes are better and costs similar or lower, depending on the person’s support needs.” (Fisher & Purcal, 2010, p. 540)

Non-profit organizations do not want the return to institutional living (CACL, 2010). Smaller non-profits may also not accept the housing grant option because it will only benefit larger organizations with their own funds. However
one parent and one government employee indicated that they knew of non-profits that were creating new housing using their own capital.

Governments do not want to spend any money on housing, however BC Housing has funded housing in the past and is also currently funding social housing projects across the province.

“… our project came out very near to the top the pile for BC Housing. It came to the top and they managed to cobble together some money that had been an overpayment or have been budgeted for but not used for other projects. We weren’t an expensive project, we were expensive enough but we weren’t expensive like some of these downtown hotels that are being totally renovated for single unit housing. So our project, which everybody liked, because we could show them that this was going to be way cheaper than the other options.”(Parent interviews)

7.3. Evaluation of creating a role for supporting networks

Equality of opportunity:

Province wide: 2 (50%), social economic class: 3 (50%), Total score: 2.5

As stated by STADD, all families are accepted currently into the STADD 55 Plus program if they meet the eligibility requirements. The gerontology expert stated seniors who are marginalized in society have greater difficulty accessing the community (Expert interviews 1) and the navigator role overcomes this difficulty for aging parents.

If the program was rolled out across the province, the challenge would be to have navigators available in rural areas. Little has been researched about social services to rural BC so as a proxy I will use two studies that looked at health services in BC. One study examined the difficulties rural seniors have in travelling to regionally provided services (Ryser, 2012). Currently CLBC has three regional offices and it is possible navigators would be stationed in each of the regions. The second study found no difference due to income but there were differences between urban and rural access that required more investigation.
(Allan, Funk, Reid, & Cloutier-Fisher, 2011). The implication for the policy option is there would likely be some problems accessing a navigator in rural areas.

**Capacity:**

*Total score: 1*

Capacity is determined by the number of families served by each navigator and the number of navigators. Currently STADD is testing to determine how many families can be serviced by a navigator. However PLAN indicates that there is a limited number of social networks each of their facilitators can manage (Non-profit interviews) and this work would be similar to navigator duties.

A 2008 report on CLBC service delivery provides some examples of caseloads (Queenswood Consulting, 2008). In Western Australia, Local Area Coordinators are service coordinators who supports between 45 to 60 families. This number is less than the 80 to 150 families typical of a social worker’s caseload in the Ministry of Children and Family Services, which social workers feel is challenging (Queenswood Consulting, 2008). As stated in the section 2.1.2, *Prevalence of ADDs in the family home*, there are an estimates 8,700 to 18,000 families in BC where an ADD lives with aging parents. While a family may only need navigator services to start a future plan, if there are not a considerable number of navigators, the capacity for this option would be poor.

**Effectiveness:**

*New families: 3.0 (75%), Families with a plan: 3.0 (25%) Total score: 3*

Offering navigator services to families will improve future planning. Currently, the navigator role in STADD helps families that do not know where to start or need assistance receiving services:

“It has been recognized that people don’t know what to do or how to do it or it is just overwhelming. Hence the navigator part of the role.”

(Government Interviews)

The navigator role can be effective in starting the conversation about future planning for families where the ADD is co-residing with the parents. Navigators
are also effective because they are a source of ‘good’ information. In a study on healthcare in the U.K., older and disabled people who did not have the information necessary to make health decisions could benefit from a person who knew the information. Such a person would not make the decisions but rather provide the right information (Baxter & Glendinning, 2011). The expert in disability states in some cases where the ADD lives at home, these families may not be well-connected to the supports and services as are other families and as a result need more guidance (Expert interview 2). The older generation of parents is less likely to have been proactive on future planning (Expert interview 2). The navigator also creates an integrated support network and these networks include more support and services than an informal network can provide.

**Stakeholder acceptance:**

*Families: 2, Government: 2, Non-profits: 2, Total score: 2*

Parents, for the most part, will embrace the concept of an integrated support network. The role of a navigator assisting in future planning has not been studied, however navigators in the health field have been evaluated. There are several benefits to patients when navigators are part of their care: navigators are a source of social support, especially if the client has a weak informal network; navigators respect the wishes and privacy of the client; and navigators can build strong support networks (Palos & Hare, 2011). Patients gave high scores for satisfaction when asked to rate navigators on questions related to interpersonal and professional skills (Jean-Pierre, et al., 2012). However, the mistrust of government employees and services may be a factor for some parents:

“So they don’t have any services. So if these family members, because again if you get more remote, people like the remoteness for many reasons, some of which people are distrustful of governmental services.”(Non-profit interviews)

ADDs would likely accept the role of a navigator. Similar to the role of participating in workshops, ADDs are empowered when they can participate in decision making (Heller & Caldwell, 2006). The STADD navigator starts the planning process with the ADD and, if needed family members.
This policy would receive a mixed acceptance from non-profits. Some non-profit groups may feel the government does not have a role to play in managing support networks.

“...social planning would not be part of the government..... did not think that the government had the capability to watch over the development of the social network. That was always the principle that the government would not be paying for that. It would never become a government program where the government was paying.” (Non-profit interviews)

STADD is a government prototype and therefore the government should be fully accepting of this option, but the cost of employing navigators across the province may be considerable. The cost of the program cannot be borne by CLBC as indicated in the government findings.

7.4. Evaluating increase to respite

Equality of opportunity:

Province wide: 2 (50%), social economic class: 2 (50%), Total score: 2

The option to increasing respite would be available to all families in the province, however accessibility may be a challenge to rural areas and seniors who are marginalized. Parents participating in an Ireland study listed lack of availability in their area as a barrier to respite (Caples & Sweeney, 2011). As stated in the navigator evaluation, BC rural areas do not have the same accessibility to health services as urban areas (Allan et al., 2012), though the difference for social services such as respite have not been investigated. The second setback for the option is the possibility that marginalized seniors would not have access to the community (Expert interviews 2). Possibly, both of these conditions can affect the fairness of the policy option.
**Capacity:**

*Total score: 1.5*

Whether the policy option has the capacity to accommodate all aging parents who want to partake in respite depends on the availability of friends and family members or of service providers. As indicated in the case study finding for BC, the $2,800 currently provided by the CLBC for respite allows parents to pay other non-residing family members and friends to provide the care (CLBC, 2007). However, one study on respite found that many parents received no support from other family members (Caples & Sweeney, 2011). For those aging families without informal help, they will need to apply to service providers for respite. The respite services current waitlist for respite is not known, however the overall waitlist for services is significant. The most frequently requested CLBC service is respite care (Queenswood Consulting, 2011).

**Effectiveness:**

*New families: 2.0 (75%), Families with a plan: 1.0 (25%) Total score: 1.75*

Lack of time and energy is a barrier to starting and maintaining a future plan. Older parents providing continuous care do not have time for other activities (Weeks et al., 2009). Three non-profit employees stated respite was important for easing into the transition of less parental care both for the parents and for the ADD (Non-profit interviews). Tying respite to future planning activities provides a ‘carrot’ approach; an incentive is provided to encourage parents to act on future planning. The problem is monitoring such a program to ensure the desired action is being undertaken.

A US study on respite found that caregiver well-being was increased when caregivers used the time to do something they desired (Lund, et al., 2014). The authors do go on to state that respite provides an opportunity for parents to seek out supports related to their caregiving role (Lund, et al., 2014), but it is my interpretation that future planning would need to be something the parents wanted to accomplish for this option to be effective.


**Stakeholder acceptability:**  

*Families: 2, Government: -1, Non-profits: 3, Total score: 1.5*

The acceptance of extra respite tied to future planning would be welcome by most parents but acceptance may be mixed. Not all caregivers want time away from their child. For some parents, being apart invokes strong feelings of worry and guilt (Caples & Sweeney, 2011). Whether parents accept respite where some of the time must be spent on planning for the future depends on the viewpoint of what constitutes a worthwhile use of respite time. Lund et al. (2014) showed parents experience greater satisfaction when respite time is used for an activity that they want to do.

If the respite was organized as a day program where ADDs interacted with other ADDs and trained staff, then most ADDs would support extra respite. This type of respite would allow ADDs an opportunity to establish some autonomy and ability to develop their identity separate from their family (Salvatori et al., 2003).

Non-profits organizations would strongly support extra respite:

“Respite funding is some of the best money spent by CLBC and most appreciated. Increasing respite funding would address growing waitlist pressure, keep people together with their families longer, and provide better outcomes for the person. The factors indicated above, particularly ageing, highlight the importance and necessity of respite.” (Inclusion BC, 2014)

The need to hold costs down as stated in the BC case study findings and the implementation challenges would mean that government would consider this option to be less acceptable than the status quo.
7.5. Summary of evaluation

Examining the scoring matrix and the foundations of those scores in the evaluation, there are three issues to consider with the options:

- None of the options would make the future planning situation worse off than the current status quo. In all options, the stakeholder acceptability indicates that, overall, there would be more acceptance of change than the status quo. The options would increase the number of families with a future plan and the remaining option would likely improve the lifestyle of the ADD.

- By the nature of their structure, the options that score high in effectiveness are less likely to have capacity. The capacity of these options are limited by the cost of government resources.

- More in-depth research is needed to strengthen the scoring of the options. The information that I was able to access is not complete and often represents a partial view of a complex interaction of factors.
Chapter 8.

Policy recommendations and implementation

8.1. Implement a government role for facilitating integrated support networks and an information campaign

From my analysis of the policy options, I recommend an information campaign combined with a navigator role. The two options work together. The information campaign provides information to aging parents about steps that can be taken to ensure their child will be cared for in the future. The navigator role carries on this direction by guiding the parent(s) through the process of making a plan for future supports. Creating an enhanced role for navigators would increase the number of families with a workable and known plan.

Providing information on future planning is key to reach aging parents with an ADD. Both options help parents start future planning when parents are not sure what they should do. An information campaign publicly addresses the often-avoided topic of what will happen when the parents of an ADD can no longer provide care. The information campaign and the navigator role combined can overcome the difficulty that vulnerable groups, such as ADDs and their aging parents, face when accessing information and making decisions (Baxter & Glendinning, 2011). Knowing the options open to them and how to access those options will help parents start the process of future planning.

The navigator role helps parents to start future planning, may decrease the parental fears about the level of caregiving and will assist with the management of service support networks. Improving the strength of the element of service and support is addressed in the option, remedying the area where parents feel least confident in
future planning. Planning for future supports and services, for the time when they are no longer able to provide caregiving, is the most challenging aspect that parents face when they are planning for the future. In the interviews, parents stated their greatest fears lay with the level of caregiving their child will receive in the future. In comparison, issues in housing and financial elements were not expressed to the same extent in emotional terms. No government policy can ever overcome all the parental misgivings about future caregiving, but adapting or expanding the STADD navigator role can improve the state of future planning.

**Implementation**

Both recommendations are underway in BC. The STADD navigator for ADDs over the age of 55 is currently being tested and the CLBC information campaign, *Strategy in Aging*, is ongoing. The results of evaluating the navigator position will help to inform the detail of implementations, but only the outcomes related to future planning should be considered. CLBC and SDSI are both involved in the navigator role and that partnership should continue, however the role should be managed from the CLBC regional offices.

Clearly, involving non-profit organizations in the implementation of the recommendation is beneficial. The non-profit’s ability to deliver services directly to families needs to be considered and their connections to and knowledge of other non-profit organizations CLBC, other ministries, and the community is vast. Non-profits can be partners in the information campaign as they were with *Strategy in Aging*. Non-profit organizations need to closely work with navigators or, in some cases, navigators could be recruited from their ranks. Implementation will require feedback about the recommendation and consultations from the stakeholders before proceeding.

**8.2. Limitations and Future considerations**

*Limitations of the study*

The study was limited by the lack of information on future planning in BC, the lack of parental interviews, and the complexity and breadth of supports for ADDs. The results
of the report are a start for examining how planning for the future can be encouraged in BC.

In many ways, the lack of future planning is akin to the elephant in the room. The discussion between aging parents and those who will be called upon to provide future supports, whether it is CLBC or family, needs to be prioritized and this conversation needs to be supported.

The parents who were interviewed had similar characteristics which does not fully explore the barriers facing parents with less education, income and those without a future plan. I was unable to recruit more parents in part because of the reality of their lives as caregivers. As the authors of one study commented on parents in their analysis on their low survey responses: “They may not have had the time, energy or motivation” (Caples & Sweeney, 2011, p. 70). While I generalized the parental findings of this study to represent parental viewpoints because the semi-structured interviews findings were similar to the findings from the literature review, research is recommended to explore the entrenchment of some of these barriers in the psyche of parents who have not planned.

This study cannot do justice to the myriad of organizations and informal caregivers that provide supports to ADDs and their families. As such, other barriers and influences to future planning may have been omitted and success stories in future planning may have been missed. Government’s and non-profit organization’s supports and services were especially difficult to delineate and the relationship between the two stakeholders was complex. As I was preparing the case studies, I found this to be the case regardless of the jurisdiction: BC, Queensland and Washington State. The large number of non-profits providing government-funded services and services for individualized funding made it impossible to follow all leads.

**Statistics**

CLBC and other government ministries cannot anticipate the demands for their services without statistics. Without knowing the ages of the caregivers, the income levels of the ADDs, the income level of families, the type of housing used by ADDs and demographics of ADDs in different regions of the province, any policies may not be
effective. Keeping statistics of those who required services because of a crisis will also help inform practices to avoid crisis. Creating and having the statistics publically available would help put CLBC’s and other ministries’ endeavours in perspective for the public, parents, non-profit organizations, and media. The collection of statistics is required to monitor the progress of future planning. According to Article 31 of the UN Convention of the Rights of Persons with Disabilities, Canada, as a signing state, is to undertake the collection of statistical data of people with disabilities (UN, 2007). The government is aware of this challenge.

**Individualized funding**

CLBC has had a long-standing policy of promoting individualized funding under the auspices of increasing choice for ADDs. Individualized funding is used in the USA and Great Britain (Allen Consulting Group, 2009; Ryan et al., 2012) and Australia is currently undergoing a country-wide rollout. Individualized funding has not been widely adopted by ADDs, however, as CLBC resources and funding are put under greater stress as demand for service increase, individualized funding will become more common. The consequence for future planning is two-fold: parents will be required to interact with service providers as a customer which may increase their awareness of what services are available and, secondly, families may need to develop and utilize more of their informal networks. Much depends on the amount of funding provided to each ADD under the individualized funding policy. An enhanced navigator role would have less to do with an informal network.

**Technology**

Technology will impact future planning through the delivery of services and increase the longevity of residency in housing for ADDs. In most cases, the technology has been developed to help older people maintain their independence through improvements that allow seniors to age-in-place and monitoring. Examples of technology are found in Sixsmith and Sixsmith (2008) who discuss the use of personal alarms for health crises and telecare, a monitoring system. These systems and similar ones enhance security and safety, reduce the need for round-the-clock care, and may facilitate keeping people in their homes longer (Sixsmith & Sixsmith, 2008). During an expert interview, advances in technology were also proposed as possible future factor in
caregiving. Apps, programs for smart phones and computers, could serve both caregivers and the ADDs. Interfaces could be set up for those with cognitive challenges allowing the ADD empowerment and independence (Expert Interview 1). Currently, the use of technology in caregiving for ADDs needs additional time and research. Future planning may well be impacted by the future.
References


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Appendix A.

Semi-structured Interview Schedule for Experts (Disability and Gerontology)

SFU MPP Graduate Research Interview Schedule
Supervisor: Judith Sixsmith
Primary Researcher: Janine Twist

Research problem:
This project examines the facilitators and barriers for future planning facing aging parents who are currently providing caregiving to their developmentally disabled adult child who is living in the family home in B.C.. Parents who have raised and provided caregiving to their disabled child find it increasingly difficult to continue their efforts as they age and face their own health challenges. When parents must stop providing caregiving due to aging/health reasons, a crisis or urgent situation may occur for the family and for the government agencies providing services. Increasing the prevalence of future planning will facilitate planning for future demand on government resources, and also reduce the uncertainty faced by the family in regards to the future housing and services. My objective is to identify influences and to make recommendations to mitigate any barriers and strengthen facilitators.

Purpose of interview:
The purpose of this semi-structured interview is to obtain your insight, opinions and perspective on aging families with a co-residing developmentally disabled child and the influences these families might face with respect to planning for the future.

The interview is semi-structured; the interview will be a conversation and may include the following topics:

Is there a problem with the prevalence or workability of future planning currently done by aging families? Will it be more or less of a problem in 5-10 years from now?

What are the family dynamics and routines with a developmentally disabled adult child?

What are the family dynamics and routines in an aging family?

What influences the support available from other family members?

Available resources and support from community and government?

Do supports from different sources (government departments, non-profits, community, family) work together or not work together?

In practice, what are the influences and challenges to planning for the future for the elderly? For developmentally disabled?
Do government policies help? Are there shortcomings?

What can be done to facilitate future planning for aging families living with a developmentally disabled child?
Appendix B.

Semi-structured Interview Schedule for Government employees

SFU MPP Graduate Research Interview Schedule

Supervisor: Judith Sixsmith
Primary Researcher: Janine Twist

Research problem:
This project examines the influences and barriers for future planning facing aging parents who are currently providing caregiving to their developmentally disabled adult child who is living in the family home in B.C.. Parents who have raised and provided caregiving to their disabled child find it increasingly difficult to continue their efforts as they age and face their own health challenges. When parents must stop providing caregiving due to aging/health reasons, a crisis or urgent situation may occur for the family and for the government agencies providing services. Increasing the prevalence of future planning will facilitate planning for future demand on government resources, and also reduce the uncertainty faced by the family in regards to the future housing and services. My objective is to identify influences and to make recommendations to mitigate any barriers and strengthen facilitators.

Purpose of interview:
The purpose of this semi-structured interview is to obtain your insight, opinions and perspective on the resources available for aging families with a co-residing developmentally disabled child, the actual process, and the barriers these families might face with respect to planning for the future.

The interview is semi-structured; the interview will be a conversation and may include the following topics:

Is there a problem with the prevalence or workability of future planning currently done by aging families? Will it be more or less of a problem in 5-10 years from now?

What is the perception about the number of unregistered developmentally disabled adults?

Has the number of services demanded increased or decreased over the past 5 years? Will demand increase or decrease over the next 5 years?

What is the actual practice of registering a developmentally disabled adult?

Are there a number of urgent cases involving aging families?

What resources and what level of funding does government provide?
What are the processes or constraints that make it difficult to provide government services to families of developmentally disabled?

How closely does the government work with the service providers? Are the services and housing available in all parts of the province?

What is the procedure for providing for services with so many possible service providers? Is there choice? What if a service provider does not exist?

How long are the wait lists? Are there some types of services or housing that have longer waitlists than others? What can be done about waitlists?

What can be done to facilitate future planning for aging families living with a developmentally disabled child?
Appendix C.

Semi-structured Interview Schedule for non-profits

SFU MPP Graduate Research Interview Schedule

Supervisor: Judith Sixsmith

Primary Researcher: Janine Twist

Research problem:

This project examines the influences and barriers for future planning facing aging parents who are currently providing caregiving to their developmentally disabled adult child who is living in the family home in B.C.. Parents who have raised and provided caregiving to their disabled child find it increasingly difficult to continue their efforts as they age and face their own health challenges. When parents must stop providing caregiving due to aging/health reasons, a crisis or urgent situation may occur for the family and for the government agencies providing services. Increasing the prevalence of future planning will facilitate planning for future demand on government resources, and also reduce the uncertainty faced by the family in regards to the future housing and services. My objective is to identify influences and to make recommendations to mitigate any barriers and strengthen facilitators.

Purpose of interview:

The purpose of this semi-structured interview is to obtain your insight, opinions and perspective on the government resources available for aging families with a co-residing developmentally disabled child, the concerns for aging and developmentally disabled, and the barriers these families might face with respect to planning for the future.

The interview is semi-structured; the interview will be a conversation and may include the following topics:

Is there a problem with the prevalence or workability of future planning currently done by aging families? Will it be more or less of a problem in 5-10 years from now?

What is the perception about the number of unregistered developmentally disabled adults?

What service do you/organization provide for families co-residing with developmentally disabled child? How do families tap into your services?

From your service/advocate provide point of view: what are families saying about government-funded services?

How long are your organization’s wait lists?

Has the number of services demanded increased or decreased over the past 5 years? Will demand increase or decrease over the next 5 years?
Do you work together with other service providers or other government agencies?

Do you feel the needs of aging families with a developmentally disabled child are met or not met? Are certain services more important than others? Are there any cases with aging families that are urgent?

Do you/organization currently provide a part in future planning for families?

What can be done to facilitate future planning for aging families living with a developmentally disabled child?
Appendix D.

Semi-structured interview schedule for parents of a person with a developmental disability

SFU MPP Graduate Research Interview Schedule

Supervisor: Judith Sixsmith

Primary Researcher: Janine Twist

Research problem:

This project examines the influences and barriers on future planning facing parents who are currently providing caregiving to their child with a developmental disability, who is living in the family home in B.C. When parents must stop providing caregiving due to aging/health reasons, a crisis or urgent situation may occur for the family and for the government agencies providing services. Increasing the number of families with a future planning will reduce the uncertainty faced by the family and allow the government to prepare for the future demands for housing and services. My objective is to identify what influences future planning and to make recommendations about overcoming barriers and inform policy makers about the strategies parents have used.

Purpose of interview:

The purpose of this semi-structured interview is to obtain your insight, opinions and perspective on the government resources available for aging families with a co-residing developmentally disabled child and the barriers families might face with respect to planning for the future.

The interview is semi-structured; the interview will be a conversation and may include the following topics:

What started the future planning process for you or what started you to think about the future planning process?

How did you find out about what you needed to do for future planning? What source(s) did you use to find the information?

Did you require legal advice? Financial advice?

Did you involve your son or daughter with a developmental disability when you started planning?

Did you involve other family members and friends?

What may have hindered or slowed down the process of making a future plan?

What are your concerns about future planning or about your plan?

What do you recommend other families do?
What can the government do to improve the ease of future planning or to encourage future planning?
Appendix E.

Parent Interview Findings

Interviews and characteristics of the interviewees:

A total of five interviews with parents were conducted. Two parents were from Vancouver Island and three parents lived in the lower mainland. As per SFU ethics, all parents who were interviewed contacted the researcher after being referred by a non-profit organization and all parents had a future plan. Two of the interviews were face-to-face and the remainder were over the telephone. Four of the interviews were with the mother and one interview was with both parents.

Currently, all the parents had similar life states. The personal characteristics were freely disclosed during the interviews. The ages of the parents ranged from 67 years old to 70 years old. All parents were educated and had worked outside the home, and indicated they presently had good incomes. Parents were connected to society, and four parents were involved with non-profit groups, including being part of a board. Parents were articulate and knowledgeable about future planning, government policies and supports, non-profit supports, and other families’ situations. The parents were in their own words “planners”; they actively sought out information and organization or people who could help them attain the life they envisioned for their child and they were goal-focused. None of the parents were currently residing with their child, instead the adult children were residing in an apartment, or an apartment building or a group home.

Information about the children was volunteered by the parents during the course of the discussion. Their children ranged in age from 30 to 46 years. Two children had an assessed mental age between 4 to 8 years, one had a mental age of 13 or 14 years, and two were not indicated. Three children exhibited behavior that made socializing or having a roommate challenging. Four children had siblings or step-siblings.

Parental stance on future planning: (Best Practices)

For the parents who were interviewed, future planning included their child leaving home and financial planning. All parents eventually reached a state where they knew their child would have to live away from them; some parents had always felt their child would leave and for others this state occurred more recently. Parents felt the need for a long term, sustainable plan for when they would no longer be around for their child. Many started with a feeling it was the right thing to do for their child and for them.

“In a philosophical way, if people can start working on accepting that their child is going to need a life apart from the family, whatever form it may take, that you really do have to face up to that. I don’t think it happens as much as it did but parents who hang onto their child and then they get old, and all the child knows is living with their parents, then when the parents die it’s a shocking transition. I didn’t want my son to have to face anything like that. Losing your parents is bad enough but not having any security or stability or having the world totally bewildering is even worse.” (Parent interview 5)
To come up with a future plan, one parent firmly stated “you must know your child” (Parent interview 2). Parents spoke about their children using straightforward comments and stories. They acknowledged their child’s limitations and challenges but the disabilities did not define who these kids are to the parents. The parent’s stories and comments illustrated their child’s personalities. Often their kids surprised the parents with their spirit, their willingness to accept or want change, and their understanding of the situation and others around them.

“I used to have to wash my daughter’s hair, her elbows are permanently bent because two bones are fused so she has limited use. When she moved out, that was one of my biggest things, I was thinking every other day somebody needs to wash her hair. But she figured out how to wash her own hair. You also have to let those things happen. If they really want something, like their own place, they will figure it out.” (Parent interview 1)

“I’ve watched them at meetings, and they did a group process and I used to teach this a bit and I was absolutely stunned at the group process taking place. They were celebrating somebody’s birthday and they had to say something, they had to say something about the person. They went around in a circle and I was going to say something but I got choked up. I said to them, I’ve worked with senior high school students but what I’m watching here is amazing.” (Parent interview 2)

Parents taught life skills to adult children in order to prepare their child to live as independently as possible. The process of teaching life skills occurred over many years and, by judging the progress of the skills, parents felt more comfortable with their adult child leaving home. Parents felt their child’s life skills continued to progress after they had left the family home.

“...we started off with a lot of baby steps at home. First of all we started doing life skills, shopping, cooking, and we got him his own phone and we had him paying phone bill. A lot of things that would be involved in independent life. We did a lot of that at home. We got him to do his own laundry and look after his room. A lot of things like that which over a few years we thought that we could actually try it for real.” (Parent interview 5)

“...it takes years to teach these kids things. They very slowly will learn. Like the kids that now make their breakfast and lunch might also learn how to make their dinner. It takes months for them to learn how to use a washer and dryer. They now can do it. All of these life skills take an incredible amount of time. But they do get there.” (Parent interview 3)

Parents felt varying levels of “peace of mind” from having a future plan in place. Parents felt they had done their best to ensure their child’s future would be secure, but felt nothing was truly secure. In three interviews, parents expressed mixed feeling on the security of their plan; feeling secure about parts of their plan, usually the financial
support and feeling unconfident about housing and support. Two different ends of the spectrum are listed in the quotes below.

“And you have to let go. I think that parents have to be up to let go and have confidence in the program.” (Parent interview 2)

“A lot of us hope and pray, that our sons and daughters will pass away before us so they will not have to encounter all of our fears.” (Parent interview 4)

Parents were strong advocates. Three of them contacted their MLA and other politicians to get what they wanted for their child. They pushed, they created crises. They used face to face meeting with politicians and ministry officials. It took years to get what they needed from government.

“When you got a group of families trying to get something off the ground, you have to pester and you have to push and you have to go to the top. You have to really work on it.” (Parent interview 3)

“You have to figure out who can help you, who can figure this out. You go a political route, you get involved with CLBC so they actually know who you are, you get involved with the community council, so it wasn’t just a piece of paper that they could shove off to the corner of the desk. They had to meet with me in person.” (Parent interview 1)

“…our project came out very near to the top the pile for BC housing. It came to the top and they managed to cobble together some money that had been an overpayment or have been budgeted for but not used for other projects. We weren’t an expensive project, we were expensive enough but we weren’t expensive like some of these downtown hotels that are being totally renovated for single unit housing. So our project, which everybody liked, because we could show them that this was going to be way cheaper than the other options.” (Parent interview 3)

Three parents stated that future planning was a process. All parents indicated it has taken years to get their future plans to their current stage and their plan was always being adjusted or updated. Despite the work involved, parents themselves appeared to have benefited also from having a future plan. As future plans, especially residency for their child went into action, parents were able to reduce their daily caregiving and to even take vacations. All parents recommended that other parents start their future planning now. Parents need to be encouraged to put something in place financially and for support. Plans can always be modified as circumstances change.

“What I would tell them is start early. Just like we did and I still don’t feel like we finished, it is a process.” (Parent interview 4)
Information about Planning:

Four parents received information about future planning through workshops facilitated by non-profit organizations. Workshops put on by PLAN and local non-profits were listed as an impetus for future planning. Newspaper articles, brochures and word of mouth were secondary way to find out about planning. The parents recall workshops as focused on financial and legal issues of future planning. Parents were instrumental in spreading the planning information they learned to other parents. One parent noted that non-profit organizations should be given funding for educating parents about future planning.

“I must have read something, I read two newspapers a day, and I must to read something in the paper and said oh hell that makes sense.” (Parent interview 2)

“We have gone to several workshops. PLAN has put on workshops and we have gone to a series that they put on, on wills and estates, finances and housing. PosAbilities also, combined with BACI, put on workshops a couple of years ago covering all of the same things.” (Parent interview 4)

Parents did not use the internet to find out information on future planning. Four parents stated they used the internet for researching information about other topics or activities, however they did not want to use the internet for future planning. However, one parent stated it would be great to have a website of lawyers who were experienced with doing legal work for people with disabilities.

“I find it just sucks you dry. I just watched people. I’m not anti-technology but I don’t overuse it. I can’t be bothered.” (Parent interview 2)

“There should be a website or something lawyers who have done this, who can deal with people with developmental disability. So I don’t waste my money going from lawyer to lawyer, I can go right to a website that says these people have this as part of their practice.” (Parent interview 1)

Support:

All five families said their children cannot live without support or supervision. “Independence” was a term used to describe living outside the family home. Support and housing issues were intermixed.

“We call it independent living with support. That’s an important concept because none of these children are able to live totally independently. They have varying disabilities and they all have developmental disabilities.” (Parent interview 3)

All parents currently provided some level of caregiving and support to their adult child. Parent did not always recognize the caregiving they provided or identify it as such during
the interviews; instead they talked about: checking up, managing, going over, taking their child to coffee shops and other places, helping with shopping, dealing with issues requiring money or payments, being at doctor’s appointments, driving, laundry, helping them with meals and dealing with crises usually related to behavior.

“...it’s like we’re sort of managers of his life so to speak. He does amazingly well but he can’t handle his finances. He needs that, he needs a lot of help with that. We like to check to make sure everything’s moving smoothly, he has his own apartment, so he needs help with all the maintaining of that, and helping him keep his independence. And there’s something about things that parents do for their children that I don’t think can necessarily be duplicated.” (Parent interview 5)

“Because I need to be close by, I need to be the background. But I do things behind the scenes and she doesn’t have a clue about some of the stuff that I do.” (Parent interview 2)

Parents valued the government-funded support that their child receives. The families had a good relationship with paid support workers and trusted the employees to report any concerns. Two parents felt support workers were not paid enough.

“With my son we were fortunate to get some funding from CLBC. So we get some support from their independent living program which in the last few years, especially as my husband and I have been getting older, has been really fantastic.” (Parent interview 5)

Two families stated their child was employed part-time. One person stated they knew of other children who worked. One parent indicated employment gave structure and made their child feel valued.

When parents spoke of support networks, they usually mentioned the person or people they had named as a trustee. Families did realize the caregiving would need to be continued but this section was uncertain.

“What we would like to see is a circle of support set up, where maybe one person looks after her finances and the other one makes sure that she is going out to social outings outside of her group home. Someone else maybe checking to see if she has appropriate clothes. So it doesn’t all fall on one person.” (Parent interview 4)

Families implied that they expected or desired that the current mix of paid supports and informal caregiving would continue in the future. Only one family was currently paying an organization to maintain a support network. Three parents also considered the non-profit organization and employees as part of the support network, though it was not clear if they had formally expressed this to the non-profit organization. In part, this train of thought occurred because they strongly associated their child’s current residence with government-funded supports. With the exception of financial trustees, four parents did not mention whether anyone in the informal support network had assigned duties or
assume a leadership role. Only one parent with an informal network continually updated the child’s support plan to include duties.

“Yes it’s all in the details. You can have a big plan, like a goal, but you have to figure out how you going to get there. Everyone has responsibilities and who is going to do it and by when.” (Parent interview 1)

**Barriers to Support:**

A major hurdle for future planning is creating and maintaining a support network. Identifying and, then, asking people to be part of the support network was a challenge. Some parents felt their family size and social network did not give them enough candidates to create a support network. Some parents considered the cost of creating and maintaining a support network through planning organizations to be too expensive. Even the parent with a managed network acknowledged support networks can be challenging and parents need assistance as indicated in the following two quotes.

“That is one of the greatest hurdles of the network. It's a simple concept but actually finding people is not that easy. So what they do is look into your own network, your family and friends, and see if there’s something that could work. Most of the people that we have in our network are from our own connections.” (Parent interview 5)

“People may come and go but we want the network to be in place. That’s why we need the organization because I think we could try to form our own network but we couldn't keep it going.” (Parent interview 5)

Three parents expressed their concerns over future support when they died; the level of caregiving that their child receives in the future may not meet the standard they hoped for. In all cases, the ADD was currently living outside the home with the majority of the daily support being provided by government-funded services or by the ADD themselves. More research is needed but the fear appears to be strongly linked to the perceived vulnerability of their child. Speculatively, the parents concern may be linked to the caregiving parents provided because this caregiving provides social inclusion for the ADD and also provides a quality control check, allowing for advocacy, on the government-funded services as indicated in the quotes below.

“We still have a lot of concerns about all these things working. They are working very well when we are still here. The big question is “how are they all going to work when we are not here?”” (Parent interview 5)

“I think we all agree that it is very scary to think how they will be looked after, after we are gone. Will other people care for them, obviously not as much as we do, but will they care for them enough?” (Parent interview 4)
Government funded support hours were necessary to support the ADDs in their current housing environment. Parents depended on the government-funded support that their child receives to reduce their caregiving role. Parents worried the services would be cut or that increased services needed as their child aged would not be there in the future. There is concern that the government won’t come through with the funding.

“Now if the government doesn’t come through with funding for our CLBC eight hour shift in the afternoon, we could fall apart.” (Parent interview 3)

**Financial/Legal Support:**

Starting a financial plan was the first step in future planning. All families had solid financial plans in place for their child; all families had a will, various trust funds, and an RDSP. All parents knew about financial planning. Parents had used law firms when setting their wills and trusts to ensure the outcomes would maximize the funds and government monies available to their child. Usually, a sibling and one close family friend were named as trustees. In one case, the trustees were already managing all the financial affairs of the ADD. The families praised the RDSP for its federal funding and they strongly recommended all families apply for an RDSP. Four of the parents interviewed stated they had a representation agreement and two had power of attorney for their child. The families were not worried about future finances for their child even though they understood their child’s future income would be close to the poverty level. They felt their child would be comfortable as they aged.

**Barriers to financial/legal support:**

Lawyers can be expensive and may give the wrong advice. Some lawyers do not correctly set up wills and trusts when the beneficiary is a person with developmental disability. Parents also noted the wide range of prices charged by law firms to do a will.

“One thing I did find out is that not many lawyers understand the best way to prepare a will for people with development of disabilities. I must have, in the past 10 years, redone my will four times because I found out something was not done right.” (Parent interview 1)

Two parents expressed that the PWD regulations needed to be updated. The monthly amount is too low and the limitations on what a person can earn is also too low before it is clawed back.

“She lives on the poverty level anyway with basically what she earns. She’s capable of earning more but it’s kind of a catch 22.” (Parent interview 2)

The financial situation of the parents affects their ability to contribute to RDSPs or to set up trust funds. All parent participants were currently able to contribute to these funds but two had experienced a marriage breakdown that strained their finances or ability to manage their child’s trusts. Divorce and single parenthood hinders financial planning.
The DTC application is difficult to word correctly, yet is necessary in order to apply for the RDSP. Most parents stated their child could not live without support, could not earn a livable wage and could not handle money yet one parent had their child’s DTC application rejected the first time. Parents felt the DTC can be a challenge.

“They have to have this disability tax credit which is daunting to apply for. And also the process of applying for the plan can be a little daunting. So I think that people just don’t have enough support to get through the actual bureaucracy of it.” (Parent interview 5)

**Housing**

Housing was a significant part of future planning and, for all five parents interviewed, this entailed the ADD leaving the parental house. In four cases the parents, not the ADD, took the initiative to move their child out of the family home. Four parents, including the parent of the ADD that wanted to move, stated that their children were happy with their living arrangements and called these places home. Parents advocated and pushed to get the housing they felt best suited their child. All parents expressed satisfaction with their child’s current housing meeting; the housing allowed for independence but also accommodated their child’s personality and behaviors. Four families had government-funded accommodation and one family supplied their child’s accommodation. Four ADDs lived in separate apartments or units and one lived in a group home. Families had different reasons for moving the ADD out of the home. Three parents stated it was something they had always planned and, as they aged, housing planning became a higher priority.

“Well, when he was still living with us I always knew he would have to live apart from us in some way. I was hoping that he would be up to live on his own because he’s developmentally delayed but he also has a lot of autistic traits. So being on his own is really his ideal environment. I just knew that for his future life, for his optimal life, and for us he would have to have something away from us whether it was a on his own or in a group home or whatever. So I just always knew that. Eventually we have to do something for him that way.” (Parent interview 5)

“I had no specific plan in mind other than to find her place that would be appropriate. That’s the plan but it was a little bit sketchy.” (Parent interview 2)

Housing location is important both for community inclusion and allowing parents to visit or check-in on their children. Parents still provided caregiving and visits to their children and their children’s current housing situation was close by. One parent spoke about the importance of a community that welcomed and got to know people with disabilities. Since the ADDs do not drive, community amenities such transit, shops, restaurants, medical/dental, as well as community programs, activities and employment should be within walking distance or bus trip.
Barriers to housing:

Parents felt there is a lack of housing choices given by CLBC. None of the ADD lived in homeshare accommodation. Home share was not viewed negatively but home share was not considered a good fit for their child.

“And the other thing is that parents don’t get to really choose the residence or placements that they want to have the child in. You have to take what you get. It could certainly be better.” (Parent interview 5)

“All you get is: living with family, living in a group home which they are closing anyway, and the big one is home share, adult foster care.” (Parent interview 1)

The waitlist for appropriate housing was a barrier to moving forward on the future plan. Parents recognized that CLBC is crisis driven. After following the regular channels and waiting, three of the families raised their situation into a crisis to get housing. Health and safety was the major reason cited by aging families. One parent indicated they waited seven years for housing.

“Right now they’re planning is focused on crisis planning. They wait for crisis is to occur before they do any planning. One of the reasons we got funding is we came under a health and safety criteria. Just because we were getting older and we both had some health issues that made a difference.” (Parent interview 5)

“I have learned you have to create a crisis. So I did. I told them I was retiring in two years and my husband was working up in _____. I said “When I retire in two years I’m going to move up to ____ to be with my husband. My daughter doesn’t want to move. It was her community, her doctor, her dentist, so you’ve got to figure out how you’re going to support her when I go”. So I created that crisis. They dragged their feet on providing what was needed until the two years were up.” (Parent interview 1)

Aging-in-place and housing permanency are factors in planning for the future, especially when the ADD was in government-funded housing. In two cases, the parents indicated CLBC had considered moving their child out of their current accommodation and that they were prepared to fight any such move because they did not feel it was in their child’s best interest. The children are already adults in mid-life and parents were not convinced that the government had planned housing for aging.

“Because the concept that we had, along with the community aspect, is the kids could age in place and that they wouldn’t be shuffled around. The government’s what they offer in terms of home, home share or group homes, this would not work for these kids.” (Parent interview 3)
“We looked into this enough, but it is my understanding that there is not enough, if any, appropriate places for the developmentally disabled who are aging. ... But especially for Down syndrome, they used to die fairly young, and now they are living longer. Other people with disabilities are living a lot longer. ... A lot of them are having dementia at an early age. So what you do with this population that is aging and requiring almost nursing home care? I don’t think there’s appropriate places for them.”
(Parent interview 4)

Some parents indicated they did not have financial resources to privately pay for their child’s accommodation where their child could age-in-place with support.

We feel that at this point we’ve done everything that we can have up to this point. Our next stage is what is going to happen? ...If we die, we’re not really convinced that he can stay in his own place. Then what, then what’s next? There’s not a lot out there. We can’t afford to put him into an assisted living place with seniors. So we have to choose something that we can get some help with and that’s quite a limited choice. So there’s a lot of uncertainty around that. (Parent interview 5)

One parent pointed out that the negative view of institutions had impacted the number of housing options open to people with high needs and behavioral problems. Yet other ministries offer housing to other vulnerable groups in society that are essentially institutions complete with common rooms and kitchens.

“The architect came on board and drew it up but it never went anywhere because the government looked on it as an institution. But my goodness, we have these people living in assisted living that have their own apartments yet they get assistance with medications and eating and dressing. They all eat in a common dining room. I don’t see the difference. How come it’s okay for them but not okay for our daughter?”
(Parent interview 4)

**General Barriers to Planning:**

Parents use their time and efforts to provide caregiving for their adult children, leaving less capacity in their lives for future planning. Two parent stated that caregiving is exhausting, with one further explaining it was emotional exhaustion, and this state decreased the desire to start a future plan.

“Having a child with a developmental disability can be exhausting. At the end of the day you are tired and the thought of doing something more, you just don’t want to do it. “Do I have to do that”? So I think there’s that reluctance”. (Parent interview 1)
All parents acknowledged information on future planning is not reaching or being prioritized by the other parents. Three parents relayed stories about other parents that “haven’t a clue” about future planning.

“So they were all living at home and the parents were getting older and the kids are getting older too. Either they didn’t know how to plan or they were sticking their heads in the sand and afraid to plan. There wasn’t any direction.” (Parent interview 1)
Appendix F.

Provincial Government Findings

The interviews:
Two in-person interviews were conducted each with two participants:

- One interview was with the CLBC team that was developing a strategy on aging. The team was made up of a CLBC manager and an independent researcher who was contracted to work for CLBC.

- One interview was with two government employees involved with Services To Adults with Developmental Disabilities (STADD), a trial program examining ways to make the government services more seamless to the ADD through the use of a navigator.

Government Stance towards future planning:
Services to adults with developmental disabilities are not mandated. The government offers supports and services as an option to improve the lives of ADDs. CLBC lacks funding for dealing with the growing number of aging ADDs. As people age housing and supports may be needed that are different from the current offerings and CLBC is not responsible to create new supports.

“The problem is that everybody thinks that people with developmental disabilities are covered by the government. They're not. All of what is coming down the pipe as they age, no. CLBC has no money to be responsible to this cohort. The funds they received are not directed at aging.” (Government interviewee 4)

The government is committed to carrying out the same funding level of supports and services but the future delivery of those supports and services and the details of coverage might change. The government does not want to increase funding. CLBC interacts mostly with service providers who deliver the services and interacts to a lesser degree with families or ADDs.

“The government has always delivered services. I don’t think the services will disappear. I think we have to reimagine what those services will look like. And ask community to take more responsibility. We’ve done a brilliant job of getting in the middle, such that community does not feel that they have a responsibility.” (Government interviewee 4)

“The key part about that, because a lot of things boil down to money and resources that aren’t always available, we are crown agency and we have
to stay within our budget, so we created a really exciting way to do this strategy.” (Government interviewee 3)

The government wants to change the culture surrounding support and services for ADDs. CLBC and the provincial government are focusing on transitions caused by aging within the ADD population. The strategy on aging and STADD are responses to the relatively recent growing population of aging ADDs. In part, this is a change is directed at ADD dependency on government-funded services, however education is key to changing the culture overall. The government acknowledges they are crisis-driven and know the demand for their services will be increasing as families age.

“We end up giving people a challenge to look at the differences they want to make and make that difference. So it’s not just about the things that CLBC has to do, it’s about anyone who cares for an individual with developmental disabilities. What you can do for yourself to make those differences.” (Government interviewee 3)

“What we are trying to do with our staff around aging is saying “you know exactly how old the people are in the region. Someone is going to be 50 next month, maybe we should find out if things are going well and if we need to do some planning”. That is a teaching we are trying to do. We are not there yet, we are trying to do it. This is what this work is all about. We want to do a whole competency-based training for our staff around aging.” (Government interviewee 3)

Information about future planning

The government has been using many channels to increase the awareness of future planning and disperse information. Internet resources, brochures, exercise booklet, forums and workshops provide information to the public. It is difficult to measure the success of the first three channels but workshops and forums are well attended. Approximately 4,000 service providers can access CLBC resources on future planning.

“We are trying to create a resource that helps families, that help service providers, helps individuals, by sharing good practices that come up.” (Government interviewee 3)

“…we contract many thousands agencies and they are going to use their own spin on what they think financial plan should be, what a support network is. However if they turn to CLBC resources, there is a clear definition of what that is.” (Government interviewee 3)
Support:

STADD recognizes that there are many definitions of a support network. Informal support networks include family and friends who provide voluntary help for daily living or may provide longer term decision making. Networks managed through privately-paid fees are an example of informal networks. Healthcare services, government services and government-funded supports combined are the formal support network. In most cases, the members in formal and informal networks operate separately from each other. The integrated support network offers the widest range of decision making and supports by incorporating informal networks and formal support networks.

“They are already sort of the integrated support network, but they may all be operating in silos from each other and working towards the same thing.” (Government interviewee 2)

“Convene an integrated support meeting. It could be family, friends, service provider possibly, and the key partners like health and CLBC, maybe the PGT, and have the conversation. So everybody knows what’s going on, that is the piece.” (Government interviewee 2)

Barriers to support:

Areas of province exist where ADDs and their families cannot get the services they need because the non-profit service organizations do not provide these services. Some non-profits are too small and lack the staff and expertise. For example, whether supports are available to come into an ADD’s home depends on the non-profit organizations in the area. The size of the non-profit and their financial status impacts the services they can deliver now and down the road.

“There are some changes being made to accommodate the person who has the family home as their asset and the ability to bring in support. It is not out of the question. Where you live challenges what you can access, the degree of innovation a service provider demonstrates, but one of the commitments that CLBC has is that people can live in their homes and supports will come in. It’s finding somebody to host that.” (Government interviewee 4)

“If you’re dealing with the sophisticated agency with lots of experience: hosting home share, running lots of types of services, dealing with individualized funding, doing community support- they have the staff that can jump in and do it. In a smaller agency, there’s problems with recruitment and retention, limited services, it is harder for them to change it up. They are not big enough.” (Government interviewee 4)

Families find it hard to setup and manage a support network; having friends and family commit to following through over the long term is challenging. In addition to this
challenge, the support of the ADDs needs to go beyond the actions of informal support networks to include professionals and government-funded support. The support the ADD requires often includes Ministry of Health and CLBC supports which family-lead networks do not have.

“They really work for some families. They don’t work for all families because they are a lot of work. A micro board is a board of directors. You have to be prepared to take that on full stop. The financial stuff, the human resources, the training, all of it. Some people have the capacity and skills. As much as people say they like what micro boards give them, they are exhausted because they are always running the board.”
(Government interview 4)

“With a micro board or a family-built support network, it is unlikely that there are the professional supports involved. So then what happens, at first, is the informal network takes on the role of navigating for the individual. If there needs to be a change in supports, the individual doesn’t advocating for themselves, someone on the informal support network, if the parents aren’t, will advocate for individual. It may be somebody working with CLBC and somebody else working with health.”
(Government interviewee 2)

**Barriers to financial:**

Parents and ADDs are the only ones who can initiate and carry out financial planning for future planning. The provincial government cannot do this activity.

“There are a bunch of things to consider, wills and estates, trusts, that kind of planning has to be done because if the family doesn’t do it no one else will do it. There’s still a lot of expectations on families to look after it.”
(Government interviewee 4)

Many families may not be aware or have planned for the government-funded pension changes that occur at the age of 65 years. People with disabilities are living into their senior years and many families have not thought about how to handle the applications for OAS, GIS and possibly CPP benefits. The provincial PWD ends at age 65, depending on circumstances, and the federal pensions and securities are available only if the ADD or guardian applies for them. Families may be unaware the process applies to ADDs. Provincial benefits such as the senior’s bus pass, medical disability benefits, and programs such as Shelter Aid for Elderly Renters are also impacted by the ADDs turning 65 years.

“…it’s not that complicated. What’s complicated is figuring out which is the right form to fill out. The Service Canada site has plethora of forms on it and they no longer will mail you the correct form. You have to get explicit instructions about which is the correct form. The forms change every year so you have to get the right year. There are others aspects too.”
(Government interviewee 1)
“The other aspect of it is, once you get all these federal benefits in place, you have to request with the provincial government that it takes your PWD file and transfers it to something called Medical Services Only. If you don’t ask for it, it won’t naturally happen. You have to know and asked for that to happen. If it doesn’t happen then you have to pay for your medical expenses. If it does happen then you receive the same medical coverage as on PWD. It’s very helpful.” (Government interviewee 1)

**Barriers to housing:**

Housing for aging ADDs is lacking and may result in ADDs being moved from place to place. The result does not allow the ADD to establish the community connections. The connections are critical for identifying medical conditions of aging for older ADDs whose disability and different communication styles make diagnoses difficult. Nuances are lost.

“The other thing about continuity in housing, is you have people that hold your story. Not somebody new who did not know who you were before. Is very difficult to assess the critical issues that are emerging with aging when nobody knew who you were when you were doing better.” (Government interviewee 4)

It is possible that costly long term care beds are used when there is no appropriate housing. The number of ADDs in long term care facilities is unknown. If it is unsafe for a person to go back home, usually because the person would be at risk because they have no caregiver, the health system is mandated to provide support.

P: “The lack of capacity in the community for stable housing meaning that people are in grave danger of going into long-term care.

I: Housing being more suitable for people for aging?

P: Housing allows you to age in the right place, in your community where you’ve always lived. Some of the long-term care facilities are the wrong place for people to be. If you’re in a crisis that is where you would end up going.” (Government interviewee 4)

“There is no money and the person is being moved into long-term care where there is support. No one can find any extra money to sustain them during the day.” (Government interviewee 4)

The family home or house the ADD lives in may not be suitable to age-in-place. Stairs and bathroom fixtures are two examples within some current homes that can decrease suitability as one ages. Even provincial programs for senior renovations such as Home Adaptations For Independence (HAFI) are not the answer.

I: “What about the program for seniors to tap into home renos?
P: You have to have a really, really low income. And you have to have an MBA to fill out the forms. The HAFI. It’s awful to access. Even so some houses are hard to modify.” (Government interviewee 4)

**General barriers:**

Parents are reluctant to start future planning because they do not know where to begin. They have raised their child without help and have embraced the belief that they alone are responsible for their child. Now that the parents are aging they cannot break out of the role to ask for support and, as a consequence, do nothing.

“I feel that parents of kids with disabilities end up being as isolated as their children because the world has not been friendly or inclusive. They were either told to put their kid in the institution and forget about it or if they didn’t take that option and kept them at home, we are talking about folks in their 80s now, they don’t think that anybody is going to be there. So they are terrified to die because they do not know who is going to look after the responsibility. They’ve never been comfortable to believe that anyone is going to take up that role.” (Government interviewee 4)

“It’s also the thinking that a person with a disability is a burden. Parents literally say “I don’t want burden my other children”.” (Government interviewee 4)

Parents do not understand the role of CLBC or that it even exists. If ADDs are not registered with CLBC, then CLBC does not know their age or their needs.

“We have to deepen the understanding of community about what the resources of CLBC are. It is still concerning how many families don’t fully understand what CLBC does. As a consequence, they cannot avail themselves of the resources, information, or access resources because they don’t know what is out there. Some families particularly that are aging, have never touched the system because they have never asked for help.” (Government interviewee 4)

“We don’t really know how many people are out there in the province who need the services. When we did the first round of community forums, we met some people by accident which found their way to the forum. We do not know how they got there, it might have been a little public profiling of the event in the paper. And some people choose to not use the system for a variety of reasons.” (Government interviewee 4)

Facilitators and regional offices are not consistent across the province in providing services. Some facilitators are active in responding to aging requests. Requests for housing and increased support that require government funding must go through CLBC, through a facilitator. Families or, usually, non-profits rarely interact with facilitators unless the request involves money. Facilitators often do not know the families so the
request application must justify the new services; there is no personal connection. Service providers are the main contact for families seeking services.

“It depends on the facilitator. In an organization this large, there are some incredible facilitators who understand their role in a sophisticated way, who would be engaging in a pro-activity way that people need. Often they are responding to as opposed to getting in front of.” (Government interviewee 4)

“They may not be involved with the person to know them well enough. They are not a social worker or a case manager. The service provider that knows the person would probably be taking a leadership role.” (Government interviewee 4)

Improving collaboration between government ministries and government agencies could improve service delivery to people with disabilities. Ministries do not want to pay for services that they feel should be the responsibility of another ministry.

**Recommendations to improve future planning**

The navigator role in STADD can start the future planning process by providing a non-intimidating platform. By creating an environment where parents and ADDs can ask for help can be the start of future planning for families. One government manager told the story about an elderly mother who was worried about her daughter, and was afraid to ask her son for help. The mother and son had come to a forum which allowed for them to talk about their perceptions, resulting in the son agreeing to take over the caregiving. (Government interviewee 3) Starting the conversation is one of the purposes of the navigator role.

“It has been recognized that people don’t know what to do or how to do it or it is just overwhelming. Hence the navigator part of the role.” (Government interviewee 2)

“What I find is that people have been thinking about it and worrying. Even though people might also assume that the individual doesn’t want to talk about things like death or dementia or funerals, there can be a lot of assumptions that people don’t want to talk about those things but my experience so far has been that people are relieved to talk about. As soon as you have somebody who is going to say “I’m going to hold this conversation” all of a sudden people are in. People want it to happen.” (Government interviewee 1)

“The navigator meets with the individual that is referred, a consent-based referral, with the navigator and planning is done. It is called the ‘big picture’ plan process. Through that planning, the wants, needs, the conversation with the individual is essentially about what they want and what the supports are, what supports need to be in place to achieve their goals.” (Government interviewee 2)
STADD meetings are face-to-face encounters between all the stakeholders. This dimension increases the probability that some action will be taken because in-person encounters increase the level of understanding. Currently navigators in STADD also provide a follow-up role which also increases the probability of action and they update a computer system called COLLABORATE for record keeping.

“So convene an integrated support meeting. It could be family, friends, service provider possibly, and the key partners like health and CLBC, maybe the PGT, and have the conversation. So everybody knows what’s going on, that is the piece. The individual is identified, the integrated support network recognizes that with a residential support, CLBC is involved, with health issues, health is involved.” (Government interviewee 1)

“So we convene a meeting and we start to cultivate a sense that we are all part of one big team. At the meeting we will present the plan, the individual and I, and then what happens naturally is that people start to say “well I can contribute to the plan in this way”, “well why don’t I take on this piece”. So we come out of the meeting with a sense of a team approach to supporting the plan.” (Government interviewee 1)

“So we come out of the meeting with a sense of a team approach to supporting the plan. From there I would move more into the role of managing the plan. Which is following up with people: “so how did it go? You said you’re going to do this”, “oh there has been a change”. So if there’s been a change, than we can adjust our strategy.” (Government interviewee 1)
Appendix G.

Non-profit findings

The interviews:
All the non-profits had been established for decades and all were the result of parents coming together to advocate for their children for greater community inclusion and support. Seven interviews were conducted with non-profit organizations providing different types of services to families:

• Four interviews were with employees of non-profits that provided direct service and support care to ADD, three of these non-profits were in the lower mainland. All organizations provided workshops, day programs and housing options such as home share and group homes. Two organization also provided life-skills training and respite. The service organizations provided support limited to a geographical area.

• Two interviews were with employees on non-profits that provided advocacy for ADD and their families. The advocacy organizations operated provincial wide.

• One interview was with an employee of a non-profit organization that focused on future planning. The non-profit organization had two parts: one operated in a limited geographical area and the second was Canada wide.

Three of the interview participants identified themselves as a parent of an ADD during the course of the interview.

Non-profit stance on Future planning:

Non-profits organizations are the intermediary between the provincial government and the ADDs and, because of this position, have a comprehensive view of future planning. All non-profits feel strongly that much more could be done to improve the current level of future planning but that doing so is complicated and requires efforts from both families and government. Non-profit service providers work closely with both CLBC and families. The employees are passionate about serving and improving the lives of people with disabilities, however they are also realistic about the limitations to the services they provide. The people they provide services for cannot live without supports.

Non-profits, as the service providers, are impacted by the lack of future planning. The system is crisis driven because parents fail to plan, have incomplete plans or do not inform others of their plans. Individuals that did not have a support network in place, or where the networks were unknown to the non-profit organizations, delayed the delivery of support to the ADD when the parents could no longer provide care. Non-profits had to scramble to find accommodation and determine who could advocate or provide informal support for the ADD. In many cases, these crises precipitated by the hospitalization or death of the widowed mother who had provided the bulk, of not all, of the caregiving.
“Then there’s a crisis situation, and in a very short period of time we have to triage. We have to ask what services are in place, who are you connected to, are they connected to CLBC, do they meet eligibility, do they have family members nearby, neighbors, church members anyone. We have to find out if it’s short-term or long-term.” (Non-profit interview 6)

“Mom has had a heart attack and died and there is this 50-year-old adult man with a disability. Then CLBC will get calls and CLBC will be calling all agencies to see if somebody has a home share or respite open. We will all be scrambling to look for that space. It might be a short-term placement, might be something that is doable and they can stay. In some situations they may actually end up in the hospital with their family member. Or they are looking at being admitted into long-term care facility. That is a potential. That used to be very common.” (Non-profit interview 2)

All non-profits recognized that the system is underfunded and feel the strain on services will increase as more people age. Government ministries are trying to contain costs. However non-profits feel they must still press CLBC and the provincial government to increase funding in order to provide services for the increasingly aging population.

I: “You think that there’s going to be an increase in the number of aging families down the road that are going to need more support?

P: Absolutely. It’s already showing up because a lack of funding for CLBC. Families are needing more money and there isn’t the money to be found. CLBC is a crown corporation and they have to stay within their budget. If you’re MFCD you can go over your budget because you’re part of government, whereas CLBC doesn’t have the luxury of going beyond their budget.” (Non-profit interview 7)

Future planning is an ongoing process. Non-profits realize that plans change, goals change, and the people move in and out of positions for future planning. All non-profits try to get families to plan and planning takes years.

**Information about Planning**

Non-profits provided parents with many venues of information about future planning such as: workshops or courses, brochures, opportunities to network with other parents and face-to-face meetings. One non-profit spoke about developing more Internet information and web-based tools, however another non-profit reported that parents find the internet frustrating to use for searches or future planning. Two non-profits reported that they provided their own funds through fund raising for outreach to families needing future planning. The workshops or forums appeared to be successful in reaching parents but the advertising of the workshops was usually limited to word-of-mouth and a posting on their website. The majority of the workshops are focused on financial and legal topics.

“You know we did a workshop our conference last year and people want to hear about what are the options, they are more savvy now about yes
we need to do this, but what are the options, what are the financials.” (Non-profit interview 1)

“We are going to be doing this spring a series of workshops one of which is on financial and estates planning.” (Non-profit interview 6)

Non-profits approached future planning as an incremental process of providing information to parents and ADDs in a persuasive, gentle manner. Three employees pointed out that aged parents are a vulnerable group and can be negatively affected by change. Two of the non-profits recommended PATHS (Planning Alternative Tomorrows with Hope) as planning tool for the ADD, family and support network. One non-profit spoke of the “tea and cake” circuit as a gradual way to educate parents about planning for the future. Others talked about small steps.

“If we are dealing with parents in their 80s we are not going to come in and say we know best and you should think about moving your son or daughter out. Offer some respite support and get some safety short-term plan. Then have a conversation about long-term.” (Non-profit interview 5)

“When moms and dads have raised and had their loved one at home, maybe the person is in their 60s, you just don’t go in and snatch the person away. There are other things we can do and get support going in. We can be creative. We can get respite and gradually increase it as a gentle transition from being fulltime with mom and dad. There’s a lot of thought that needs to go into it. One size does not fit all.” (Non-profit interview 5)

Support:

Non-profits recognized that support networks were made up of both the family and friends plus the paid support workers. Networks involve the whole community. Setting up a support network was critical in future planning because it detailed who was going to take care of responsibilities after the parent can no longer provide caregiving.

“The idea with the social network is to have friendship and that you have different levels of friends and acquaintances and professionals that know the person and can be there some way or another. They know banker, the person at the coffee shop, and it sort of a take a village mentality. … Just that a person matters, they are noticed, they are part of somebody else’s world, and making sure that that happens. We all do this to a degree for ourselves and for people with disabilities, it takes a little outside work to make it happen.” (Non-profit interview 4)

“It’s important for all humans to have a healthy social network, particularly if the person with a disability is living with their parents and relying on their parents for support, advocacy and friendship. What happens when the parents die? The social network was a solution to say after the parents
die there will be something, people, around the person with a disability to continue to be there for them." (Non-profit interview 4)

**Barriers to Support**

Parents do not trust the government or others to provide caregiving at the same level that they provide. The high expectations become a barrier to setting up future supports for the ADDs. In some cases, the future of caregiving becomes such a huge barrier in the minds of parents that it paralyzes any other future planning action such as setting up housing and legal planning.

“So they don’t have any services. So if these family members, because again if you get more remote, people like the remoteness for many reasons, some of which people are distrustful of governmental services.” (Non-profit interview 3)

“As you can well imagine, and I’m a parent as well, it is a difficult thing to probably think about having to do but because often their son or daughter is so dependent, finding adequate supports for their son or daughter outside the home. You know a loving caring situation, is something that scares a lot of us family members.” (Non-profit interview 1)

The abridged story below indicates how the parental role of caregiver can be difficult to reconcile with future planning. The parents in this example cannot relinquish their caregiving role and as a result no future planning has been done. The non-profit employee felt there would be a future crisis since no representation agreement or estate planning had been completed.

“There is a family that we have been working with for years. The parents are in their 80s and we still cannot convince them to take the next step of future planning. I’ve tried many times… So family like that needs more support. We’ve let CLBC know this family is out there but they won’t make a decision…it’s emotional. The family, I don’t know their financial, but the house is probably paid off. But they can’t make that final decision on what they want it to look like… See, they would have a hard time deciding who should be the representative. Right now they feel very strongly that they are responsible for their children…. They cannot step out of their traditional roles of parenting. No one can do it the way they do.” (Non-profit interview 2)

Support networks require constant work to maintain which may be beyond the parents’ capacity to carry out. Support networks build on family and friends supplying unpaid service support may not endure over the long run. Siblings, and the sibling’s family, need to be well informed about the level of care needed for their brother or sister before they take over the care. Future plans must include provision for government-funded or paid supports.
“But the social network is more of an ongoing project you always want to keep on top of depending on the outgoingness of the person with a disability. It can be a lot of work.” (Non-profit interview 4)

“We need to know who is going to provide unpaid support. Because they always think that paid supports are going to be the default. So the transition plan always has who is going to provide unpaid support, who is going to take care of them. We do not want to remove our advocacy because the person who is doing unpaid support is not going to want to do that for their entire lives. We have to have an alternate plan.” (Non-profit interview 6)

“The problem of course is that CLBC does not react quickly and the best planning is not done on short periods of time. So families are having to resort to family members who feel that the situation has been thrust upon them rather than well planned out.” (Non-profit interview 3)

However one non-profit stated the government should not manage support networks but could provide funding to families for managing networks.

“…social planning would not be part of the government…. did not think that the government had the capability to watch over the development of the social network. That was always the principle that the government would not be paying for that. It would never become a government program where the government was paying.” (Non-profit interview 4)

People with disabilities were not being taught the life skills necessary for the time when the parents can no longer provide caregiving. If ADDs are not given the opportunity to develop some level of independence, the transition from family-life to life where the parents are not providing caregiving will be challenging. Families are not allowing their children to develop:

“…it’s a learned helplessness. They are not learning to be as independent as possible because they’re living in the constraints of mom and dad at home.” (Non-profit interview 3)

The waitlist for support services can be a barrier to future planning. Even if the supports are approved, there may be a waitlist. The length of the wait lists were not disclosed for support services but waitlists did exist. However turning to government-funded IF is also problematic. If the requested service is currently in the community, parents cannot use IF to circumvent the waitlist by accessing a similar support.

“Once the GSA is administered and the plan is approved and everybody agrees on what services will be provided then depending what community you’re in there is the budget, because CLBC has a fixed budget every year, it depends on what monies are left that year at any given point in time.” (Non-profit interview 1)
“Existing services may meet their needs 100%, but they are on the waitlist for those services. Individualized funding does not replace the waitlist. A lot of parents think, I’m waiting five years for home care so I will turn to individualized funding. Doesn’t work.” (Non-profit interview 6)

**Financial/Legal Support:**

Non-profits encouraged all families that they contacted to set up a financial plan. The organizations provided some assistance with representation agreements and DTC applications, but for other financial or legal information most non-profits referred families to professionals in the field such as banks, lawyers or specialized organizations. Financial planning appears to be more cut and dried in part because the government has provided structures for future planning such as the RDSP and discretionary trusts and representation agreement.

“Right like the registered disability program, you’ve got to get your tax credit set up, you got to go to the bank, you got to start contributing, you’ve got to think about a schedule about what you’re going to put in and being aware of the matching grants that are available and keep your tax up to date. But once it is going, it’s just a matter paying attention to the investment or increase the contribution, making sure you don’t go over your limits and taxes. There are a few maintenance things that are way less work than the original application. The hard work is at the beginning.” (Non-profit interview 4)

The RDSP is considered one of the best ways for families to prepare for the future, however non-profit societies felt there are still misconceptions and lack of information about RDSPs. Education is still needed to reach families about the RDSP; parents did not know that they do not need to contribute any money to have an RDSP. Also some parents did not know that RDSP are suited for younger ADDs; matching grants and bonds stop at age 49 and private contributions must stop at age 59.

**Barriers to Financial/Legal support:**

Without some sort of legal representation, ADDs cannot direct another person to help them with financial, legal or health matters. In all situations, non-profit employees and professionals such as doctors require some sort of legal representation if another person is going to speak for the ADD. Non-profits have been active in raising awareness of representation agreements however parents, and even lawyers, do not understand the laws around legal representation and the distinction between the two sections.

“A lot of times parents think that if I take care of my affairs, then my child will be taken care of. Under the law an adult child is independent, unless redeemed by the court not to be. This is why I do representation agreement workshops. They don’t understand the importance of the section 9 and they don’t get a section 7 for their child. I’ve had many parents say “I’ve left instructions in my will about the Guardian for my child” but that no longer applies once there over 18. The lawyer should have corrected it.” (Non-profit interview 6)
The structure of trusts and estates were seen as complicated. Extra income from a trust or an inheritance could stop the PWD or other disability support such as subsidized housing. Wills are more generally complicated than for families without disabilities.

“…the consequences, one of the biggest ones on writing a will is that if someone is on provincial disability or benefits those are income and asset tested. Which basically means if you’re have a certain amount of assets money in the bank or real estate property or whatever, if it hits a certain amount you no longer chargeable for disability benefits. The same with income if you’re above a certain amount you are no longer eligible for the disability payment.” (Non-profit interview 4)

Identifying a trustee to administer trusts was difficult. Many times it was a family member but the duties can be challenging.

“…so it’s not something a trustee should take lightly and there’s some people shouldn’t be doing it. And there’s a lot of families who are having trouble identifying who could be a trustee.” (Non-profit interview 4)

Family and ADD do not have enough income to privately fund housing and services. One non-profit employee pointed out that some ADDs live in the family home or with another person because they do not have access to subsidized housing, and their income or PWD does not pay enough for them to afford market rents. Living at home in many cases is not a choice but a reality. Increasing the income or funding levels to allow families to put money towards future planning was also suggested by another non-profit. One employee stated that in the lower mainland where families are asset rich and cash poor, reverse mortgages can provide some private funds.

“I think ours is quite low. … I have a friend who’s a self-advocate, he’s fairly high functioning, but he lives with his sister because where is he going to get an apartment for that low an amount a month?” (Non-profit interview 7)

I: “…are there very many people who can privately fund services?

P: They could, they would have to have some significant funding. The majority of the cost is the staffing. And you cannot pay babysitting rates.” (Non-profit interview 2)

**Housing**

Housing and supports were closely related in discussions with non-profits. Housing amenities and location were very important for work, transportation, safety and inclusion in the community.

“We try our best, we typically get the location. It also depends on whether employment and day program is. Transportation is a huge issue. We always have to consider transportation when we are looking at where and
whom. We put it together and we come out with options.” (Non-profit interview 5)

Home share is the most common type of government-funded housing and two non-profits spoke of the variety within this type. ADDs were carefully matched to home shares based on personality, location, and preferences and, for most cases, the matching system was considered to be a relative success.

“…home share is the label. Would home share is and what a home share looks like all depends on the person. Each and every home share is unique and individual. We really do need to qualify what a home share is. It can look like anything that the person who is requiring home support needs. It can look like your typical family. It’s the 24 seven support. Or it might look like a single person and the other person moving it, more like a companionship. Or it can look like husband-and-wife or it can look like whenever the person needs. It’s all about the matching.” (Non-profit interview 5)

**Barriers to Housing**

Housing choice and the number of housing units available are lacking for ADDs. Home share is the only model that government is currently expanding and four non-profits stated they felt that this was budget driven. The closing of group homes limited the housing choices available to ADDs. Group homes were not recommended by employees except in a few cases where medical and behavior needs were significant.

“Home share has become very popular because it is a less expensive model. And from what I've heard from some of the service providers they are being told it is the only model.” (Non-profit interview 7)

“That is a big part of why we have people in home shares, because group homes have been closed.” (Non-profit interview 5)

The home share model may not be fit older adults who are seeking to age-in-place. While home shares were acknowledged to be good current options for many ADDs, home shares received mixed response as an option for future housing. However, non-profits also expressed concerns on whether home shares were sustainable in the long term. One non-profit employee was concerned over the decreasing funding paid to home share operators. Three non-profits commented that home share operators can stop their contract, due to changes in their own circumstances, causing the ADD to move. One employee stated there was a waitlist because there were not enough home shares. Two non-profits knew of situations where home shares became unsuitable due to problems the ADD encountered as they aged.

P: “There are more people with developmental disabilities who want home sharing or that need a home share. We have a long waiting list of people who would like to be matched…
I: Home share is in short supply?

P: Absolutely.

I: Ok as I suppose all the other types of residences.

P: Oh yes, more so, more so because CLBC from a cost perspective, a financial perspective to the province, it’s much more economical for them to place an individual in a home share than it is in a fully staffed home.” (Non-profit interview 3)

“Some of the ladies and gentlemen we get will be living at home share are now experiencing aging issues and so the question comes up is the match still good? This is something that’s on our minds. There are still our group homes because they do provide a valuable resource. We have run into the situation where somebody is aging or has health needs. It may not be the best match anymore. It could have stairs or something.” (Non-profit interview 5)

However, parent-supplied housing may also not overcome the lack of housing for ADDs. Many parents leave the family home to the ADD in their will. Parents are unaware that the lack of supports, with the emphasis on government funded supports coming into the home, can nullify their wish to have their child remain in the family home.

“A lot of older parents do take that approach. They say “I have saved all my life, the house is paid for and I want my son to live here and they’re not moving”. I have to get them to realize, diplomatically, that that does not guarantee services will come to that house. If they die tomorrow, their son or daughter would be in the house without supports.” (Non-profit interview 6)

**General Barriers to Future planning**

Non-profit recognized that parents are often exhausted from looking after their adult with a disability and this becomes more pronounced as the parents age. Parents that do not have the energy or the education are those most at risk for not having a future plan.

“The other thing is, you have to think what families are going out and being vocal and advocating for their loved ones. These are the families that have the energy, financial ability, education. I would like to know what families are out there that have all of this because, you’ve got to understand, some the families out there, they don’t have the energy to do this. You think of Maslow, they are just trying to get their basic needs met. They don’t have the energy or the support to do all this. Are they getting the funding they require? They don’t have. They might have issues themselves. They can’t even fathom.” (Non-profit interview 5)
“So if you are getting supports one or two days a week and it’s hard to increase the services, I get calls from parents who are saying “I can’t do it, I’m exhausted”. (Non-profit interview 7)

Parents tend to put future planning off for a variety of intermixed reasons. Some parents, especially those of the older generation, are not prepared for the time that they can no longer provide caregiving. After a lifetime of providing caregiving, some parents do not know how or who to ask for help. Think about planning for the future becomes an uncomfortable issue. Three non-profits employees discussed that parents either did not want to discuss future planning or did not know where to start.

“It is panic based. Or it’s like “we don’t need to worry about that now”. I think it is fear-based. They do not know who they should talk to. For some of them they have done it all on their own anyway and have done it well. They have not needed services. To go down that path is different for them.” (Non-profit interview 2)

Parents lack awareness of the government and CLBC services. One non-profit spoke about “shut-ins”, ADD living isolated lives with aging parents. Four non-profits mentioned cases where elderly parents had never used government services.

P: “And for those families, they have never had anything. They never had support into the family home.

I: They just always relied on their own friends, family or themselves?

P: Yes.” (Non-profit interview 2)

Non-profits feel that parents are unaware government services are not guaranteed: parents do not realize that CLBC services are optional. For ADDs over the age of 19, government services related to developmental disability are not required to be funded. If parents or ADDs want a service or support, the first step is asking either the non-profit service provider for information or contacting a CLBC facilitator. The CLBC facilitator determines whether the service fits the goals and needs of the ADD.

“One of the key things for families to understand is the shift childhood to adulthood and that adult services are not legislatively mandated, so there isn’t a mandated requirement that somebody receives services through the provincial government.” (Non-profit interview 6)

Language is a barrier to future planning. Many parents feel the government does not listen to their requests for services or housing. Parents describe their situation and their child in terms that are natural for parents. Forms, such as the DTC, are difficult to fill in because the form require parents to be negative about their child. If the non-profit can become involved they can liaison between parents and the government.

“Hearing the stories. Hearing the history and being able to translate that into a lingo that CLBC understands. And also being up to infiltrate those
stories with suggestions: I hear what you’re saying now what we do this? I slowly educate them about what the system does and doesn’t do.” (Non-profit interview 6)

“This is a human being we are talking about and it is so disrespectful. I get sad for parents because they’re having to put their lives on a piece of paper and share with strangers.” (Non-profit interview 5)
## Appendix H.

### Documents and webpages for BC Case study

<table>
<thead>
<tr>
<th>Documents</th>
<th>Webpages</th>
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<tbody>
<tr>
<td>Navigator support: are you an older adult with a developmental</td>
<td><a href="http://www2.gov.bc.ca/gov/DownloadAsset?assetId=5614B690A022">http://www2.gov.bc.ca/gov/DownloadAsset?assetId=5614B690A022</a></td>
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<tr>
<td>disability</td>
<td>4598AD6AB320DFEFAB5D&amp;filename=navigator-infosheet_oas.pdf</td>
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Appendix I.

Case Study: British Columbia, Canada

Demographics and government structure

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<thead>
<tr>
<th>Category</th>
<th>Statistic</th>
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<tbody>
<tr>
<td>Percentage of all population over 65</td>
<td>15.7% (Govt of Canada, 2011)</td>
</tr>
<tr>
<td>Population of ADDs</td>
<td>36,000 estimate (CLBC, 2014)</td>
</tr>
<tr>
<td>Annual median income</td>
<td>CA$54,000 (Govt of Canada, 2011)</td>
</tr>
<tr>
<td>Type of government</td>
<td>Federalism, Article 92 of Constitution Act 1982 gives provinces jurisdiction over social services (Dept of Justice)</td>
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<tr>
<td>Responsibility for ADDs</td>
<td>Family and provincial government</td>
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According to CLBC’s calculations of the prevailing population, there are approximately 36,000 adults over the age of 19 years with a developmental disability. The majority of this population lives in the family home (CLBC, 2014).

Canada is a federal state; there is a division of powers between the country-wide federal government and provincial governments as defined in the Constitution Act 1982. In the Constitution, section 92 gives the provinces the responsibility for healthcare systems and charities (Dept of Justice) which has evolved into the understanding whereby the provinces are responsible for social programs and welfare for the residents. BC’s provincial government is the primary source of disability policy and of funding and support for residents with development of disabilities.

Current supports for persons with developmental disabilities

The current supports for ADDs provided in BC primarily come from the family and provincial government with the federal government providing a lesser role. The supports can be divided into financial/legal, service and housing supports.

Financial/Legal supports

The federal government provides the Disability Tax Credit. Persons or families can apply for a Disability Tax Credit Certificate from the Canada Revenue Agency, and if eligible, can claim up to CA$7,766 in non-refundable tax credits on subsequent individual tax filings (CRA, 2014).

The province of BC delivers monthly financial assistance in the form of the Person With Disability pension (PWD) to residents over the age of 18 years with a disability. The pension is necessary because employment opportunities are minimal and jobs that do exist are often part-time and poorly paid (SPARC BC, 2009). The Employment and
Assistance for Persons with Disabilities Act (BCEA) legislates the Persons With Disability pension (PWD) (SDSI, 2014) to provide funds for daily living. Individuals with as disability are eligible for the PWD when they become 18 years old. Persons with a disability or their families must apply in person at an Employment and Assistance Center and complete a lengthy application which includes a physician’s report (SDSI, 2014). PWD provides CA$531.42 per month plus an additional CA$375 shelter allowance. The recipient of PWD may not have income greater than CA$800 per month after eligible expenses and may not have assets greater than CA$5,000, less exempt assets (SDSI, 2015). The BC government allows persons with disabilities to set up trusts to hold assets to circumvent the asset restriction (SDSI, 2012). When the ADD reaches the age of 65 years and older, the federal government pension, Old Age Security (OAS) and the Guaranteed Income Supplement (GIS) usually replace the PWD (Service Canada, 2014).

Service supports

The services and housing are not provided directly by the provincial government, but are instead provided by contractors, non-profit organizations and in some cases for-profit organizations. Persons with disabilities can only access organizations providing living services and supports through CLBC. The provincial government produces regulations concerning home share operators, group homes and minimum requirements for home care and personal services personnel which service organizations must abide. Non-profits support families, provide day programs, arrange and/or provide respite, provide employment and training to individuals with intellectual disabilities and help individuals and their families navigate ‘the system’. The most significant hold the provincial government has on non-profit organizations is the funding granted to the organization.

CLBC is constricted by its budget provided by the provincial government and is well aware of the shortfalls as it deals with climbing costs and an increasing population (CLBC, 2014). Inclusion BC notes CLBC predicts a declining average cost per client from CA$46,400 in 2013/14 to CA$43,500 in 2015/16 which can only be achieved by reduction in services (Inclusion BC, 2014).

The outcome for people with a developmental disability is to wait for their Request for Service to be filled. The December 2011 CLBC Service Satisfaction Survey in stated that 75% of families with a person with a disability have waited more than six months for a service, and 63% had waited over one year (Mustel Group, 2011).

One of CLBC’s goals is to increase the number of people using individualized funding (CLBC, 2014). Individualized funding is a payment system where the individual or representative agent has choice in the service type and service provider. (CLBC, 2009). There are two formats for choice-based funding: 1) direct funding where the individual or agent is given the CLBC allotment to manage and 2) host agency funding where the individual or agent chooses a service provider and CLBC gives the allotment to the service provider to manage (CLBC, 2009).
Housing

CLBC funds four types of housing arrangements: home shares, group homes, cluster living, and supported or semi-independent living (CLBC, 2014; SPARC BC, 2009). In 2014, two-thirds of the 6,564 adults receiving residential services resided in shared living or supported living settings and the remaining third were in group homes (CLBC, 2014).

Homeshare is the model currently being promoted. Within homeshare there is a variety of living arrangements such as a basement suite, a bedroom in the house or apartment, or as a roommate (CLRP, 2008) The match between the adult with disabilities and the homeshare host is paramount to the success of the placement and a match may take up to several months to put into place (CLRP, 2008). In 2008, the average cost for housing a person in homeshare was $27,796 compared to $97,252 for group homes. The adult with a disability pays the host the rental amount of their PWD (CLRP, 2008).

Non-profits support families, provide day programs, arrange and/or provide respite, provide employment and training to individuals with intellectual disabilities and help individuals and their families navigate ‘the system’. The bulk of the funding for non-profits is through CLBC. In 2008, there were 54 non-profit housing societies that provided 889 housing units designated for people with developmental disabilities (SPARC BC, 2009). These units served approximately 4% of the 20,130 adult population with a developmental disability (SPARC BC, 2009).

Available housing for aging in place is scarce. Most housing options do not address important life transitions including aging (SPARC BC, 2009). According to the 2006 Census, people with a developmental disability living in BC reported moving to a different residence within the past year at a rate nearly double of the non-disabled population (SPARC BC, 2009).

The PWD shelter allowance does not cover the market cost of rent, therefore rent is usually subsidized by the parents of the adult with a developmental disability or by BC Housing (SPARC BC, 2009). The result of unaffordable income may be one reason adults with developmental disabilities live at home (SPARC BC, 2009). To apply for publically-funded subsidized housing as a person with a disability, an applicant must be able to live independently and be eligible for a disability tax credit or disability pension (BC Housing, 2008). Subsidized housing has long waitlists (SPARC BC, 2009).

The current supports for families with an ADD

Supports for families with and ADD are tied to supporting the individual. The two supports that do have a focus on the parents are:

CLBC provides CA$2,800 a year through the Adult Respite Direct Funding to each registered ADD. Families may choose any service provider, neighbour, friend, or relative to provide respite. All provincial employment regulations apply and records must be turned into CLBC (CLBC, 2007).

Non-profit organizations facilitate parent-support groups where parents can discuss issues. Future planning workshops, usually focused on financial planning are often arranged by non-profit groups.
Community Councils have been established throughout the province. The members of the councils are volunteers and include self-advocates, families, non-profits, and community members but the majority must be self-advocates and family members. Community Councils do not advocate or dictate policy but do provide feedback on CLBC services and work to make communities inclusive (Queenswood Consulting, 2008).

**Future planning in the political/social agenda**

The BC government is aware of aging parents with an adult child with a developmental disability and the importance of planning for the future. The need to address the issue consistently appeared in the CLBC service plans. In 2011, CLBC has produced a brochure called “As you age, do you worry about a family member with developmental disability?” which asks parents to be proactive in planning by contacting PLAN, NIDUS, a professional, family members or CLBC. On the CLBC website is the webpage “Growing Older in the Community-Aging” where the brochure can be downloaded and the joint plans between CLBC and the Ministry of Health can be obtained (CLBC, 2010).

The RDSP is a federal initiative to encourage saving and is open to all people with a severe disability. The RDSP was launched in 2008 with the passing of the Canadian Disability Savings Act and provides future funds the beneficiary can draw on to pay expenses. Persons with the development of disability or families, as holders, can open a RDSP at any Canadian bank or financial institution if the beneficiary fulfills the following three conditions: a Canadian resident, under the age of 60, and eligible for disability tax credit (ESDC, 2014). Personal contributions are not tax-deductible and the total amount of these contributions cannot exceed CA$200,000. The federal government contributions come in the form of the: Canada Disability Savings Grant, which uses a formula to match between 100-300% of the personal contribution; and the Canada Disability Savings Bond, where the bond is given, regardless of personal contributions, to those with family incomes of less than CA$43,953 according to a sliding scale. The amounts given are means tested and capped; currently, the maximum annual grant is CA$3,500 and the maximum yearly bond is CA$1,000. All government contributions cease when the beneficiary reaches the age of 49 years and allowable private contributions end at the age of 59 years. The funds are withdrawn in the form of a Disability Assistance Payment (DAP) or a Lifetime Disability Assistance Payment (LDAP) and the proportion of these withdrawals attributed to the grant, bond, and interest is taxable (ESDC, 2014). Overall, the uptake of the RDSP has been approximately 78,000 of the 500,000 eligible Canadians (Hodges, 2014).

The province of BC through the Representation Agreement Act allows an ADD-selected representative to legally make decisions on behalf of the ADD (CBA, 2012). There are two types of representation agreements: RA7 and RA9. The Representation Agreement section 7 differs from a Power of Attorney because it allows a person without full-cognitive capabilities to appoint representatives to make decisions about issues such as: health care, routine finances, legal affairs, and personal care without the person relinquishing their personhood (Nidus, 2012). Hiring a lawyer is not required but there is a CA$25 fee for creating an account and registering the document with Nidus (Nidus, 2015).

Several non-profit organizations specialize in planning for adults with disabilities with a focus on financial planning and support networks. Planned Lifetime Advocacy Network
(PLAN) was started in 1989. The RDSP and representation agreement were initiated by PLAN. PLAN also encourages the formal building of support networks and provides monitoring of Lifetime Membership agreements (PLAN, 2013). Vela Canada, established in 1990, help adults with a disability and their families to create small non-profit societies called microboards. Microboard members are friends and families who, with the individual, manage and advocate disability services for the individual and provide inclusion (Vela, n.d.). Lifetime Networks is located in Victoria and operates similar to PLAN. For each of these organizations, there is a fee for maintaining the support network and due to the nature of networks, the organizations are limited geographically.

**Innovative or unique policies aimed at future planning**

Services to Adults with Developmental Disabilities (STADD) for persons over the age of 55 years is a prototype program directed at helping aging ADDs. Currently the program is only offered in Burnaby, BC. The STADD navigators assist individuals and their families to engage in the current system and prepare for the future (CLBC, 2014). A navigator meets with individual, and records their goals and information about their needs into a database called COLLABORATE (Government interviewee 1). Given the needs of the individual, the navigator convenes a meeting with the personnel who can help the ADD as required from the ministry of health, CLBC, service providers, friends and family. Along with the ADD, the navigator presents the needs to the group and the group works as a team to support the plan (Government interviewee 1). The group is an integrated support network, combining both the informal support network of family and friends with the formal professional support network (Government interviewee 2). Different group members volunteer to take on duties or tasks to support the ADD. The navigator provides follow-up, notes the progress on the tasks, updates COLLABORATE and makes adjustments to the plan. STADD has no funding or authority but can bring both the formal and informal support teams to work together (Government interviewee 2).

*Strategy on Aging* is project involving CLBC, other ministries and service providers to support aging ADDs and their families. Workshops and forum were held across the province for parents, CLBC employees, and service providers to encourage a proactive approach to aging, including future planning.
Appendix J.

Documents and webpages for Queensland Case study

<table>
<thead>
<tr>
<th>Websites and webpages</th>
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<tr>
<th>Documents</th>
<th>Webpages</th>
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Appendix K.

Case Study: Queensland, Australia

Demographics and government structure

<table>
<thead>
<tr>
<th>Category</th>
<th>Statistic</th>
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</thead>
<tbody>
<tr>
<td>Population of Queensland</td>
<td>4.3 million in 2011 (ABS, 2013)</td>
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<tr>
<td>Percentage of all population over 65</td>
<td>13.2% (ABS, 2013)</td>
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<tr>
<td>Annual median income</td>
<td>AU$64,000 estimate (ABS, 2012)</td>
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<td>Type of government</td>
<td>Federalism, In Commonwealth, State and Territory Disability Agreements, the Commonwealth is responsible for income assistance leaving management of services and policy to the states (DSS, 2014). However, under this Agreements are bilateral agreements between the Commonwealth and each state that outline joint collaboration to improve disability services and policy (DSS, 2014).</td>
</tr>
<tr>
<td>Population of ADDs</td>
<td>Unknown, All disabilities are amalgamated into one group for policy purposes</td>
</tr>
<tr>
<td>Responsibility for ADDs</td>
<td>Family, Commonwealth, and state government</td>
</tr>
<tr>
<td>Stance towards Persons with a developmental disability</td>
<td>Australia ratified the UN Convention on the Rights of Persons with Disabilities on July 17, 2008 (AGD, n.d.).</td>
</tr>
</tbody>
</table>

Australia places developmental disability into the category of intellectual disability. Intellectual disability also includes head injuries, stroke, brain damage, dementia and autisms. Having said this, approximately 88,000 people in Australia identify as having a developmental disability (ABS, 2014). There are no statistics for the number of persons with a developmental disability in Queensland. Australia encourages the individual with a developmental disability to stay in the family home (Yoong & Koritsas, 2012).

In 1901, Australia was established as a federalist state and, much like Canada, the Commonwealth, or federal government, ceded the responsibility of hospitals, schools and community services to the states in the constitution (PEO, n.d.). Under the Commonwealth, State and Territory Disability Agreements, the commonwealth is responsible for income assistance leaving management of services and policy to the states (DSS, 2014). However, under this Agreements are bilateral agreements between the Commonwealth and each state that outline joint collaboration to improve disability services and policy (DSS, 2014). The Commonwealth holds a considerable influence on disability policy in Australia as illustrated in the following section on current support.

Current support for persons with developmental disabilities

The government of Australia provides supports to people with disabilities through the Department of Social Services, the establishment of Special Disability Trusts, payments
to carers and the Disability Support Pension. People with intellectual disabilities are not distinguished from other disabilities for the purpose of accessing government support and services (Allen Consulting Group, 2009). The state of Queensland supports people with disabilities through Disability Services Queensland which was established in 1999 (Queensland, 2013). The family and friends provide most of the caregiving for the ADD (Allen Consulting Group, 2009).

**Income support from government**

Persons with a disability can apply for the Disability Support Pension (DSP) at the age of 16 years (HS, 2015). The current DSP is a maximum of AU$776.70 per two weeks (HS, 2015) (approximately AU$1,680 per month). In addition, there is an automatic pension supplement of AU$63.50 every two weeks (AU$137 per month) (HS, 2014). The DSP is asset and means tested; funding stops when the individual earns more than AU$1,868 per fortnight or has AU$918,250 in assets. The DSP payments end when the individual becomes eligibility for an old-age pension (HS, 2015).

**Housing and service supports**

The Queensland government provides funding for accommodation and direct-care disability services. The Disabilities Service Act 2006 determines whether an individual qualifies for assistance. Adults with a disability must apply at Disability Services centres to be assessed (QLD Govt, 2013). Under the title of “specialist disability service”, support for daily living, mental health support, respite services and community access support can be made available to a person with a developmental disability (QLD govt, 2014). The Queensland government does not provide the on-the-ground services but contracts out the services to non-profit and for-profit organizations.

The Department of Social Services (DSS) provides information about services and financial supports available to persons with a disability, and directs the social policy of the Commonwealth. The DSS enforces the accreditation of disability advocacy organizations and the accreditation of organizations providing direct care. Accreditation is necessary to receive government funding.

Recently, the DSS has been advancing the National Disability Insurance Scheme (NDIS) policy for a country-wide acceptance in 2016 (DSS, 2015). Currently, the governments in Australia provide block funding to service providers based on historic cost of providing service to an area and, as a result, there is no desire to reduce costs (Curtin University, 2014). Service providers under the block system limit the access to services because they are under-funded (Yoong & Koritsas, 2012). By giving the family and individual with a disability choice in services and service providers, service providers supply the necessary services at market prices (QLD Govt, 2014). Choice is associated with planning for the future. However the NDIS has received mixed reviews on its impact on aging families. The NDIS is seen by some as a way to increase the support for older families (Copland, 2012), but others fear the NDIS may freeze the funding provided and will not be adjusted as the parents get older (Visentin, 2014).

The Queensland government provides funding for accommodation and direct-care disability services. Adults with a disability must apply at Disability Services centres to be assessed (QLD Govt, 2013). The Queensland government does not provide most on-the-ground services but contracts out the services to non-profit and for-profit
organizations. Regional offices of the Department of Communities, Child Safety and Disabilities maintain the Register of Needs, a list of people waiting for specific services (Clerke, 2015).

Non-profit organizations in Queensland provide advocacy for individuals with disabilities, advocacy for caregivers, employment services for the disabled, respite, day programs, housing, accommodation support and direct care services. To access the services of non-finals, individuals must be deemed eligible by the Queensland government. Within the non-profit sector, local groups are usually associated with a national or umbrella organization that represent the aggregated agenda on the national scene. For example, the National Disability Services is a non-profit organization that lists service providers across the country and advocates for the disabled (NDS, n.d.).

The Queensland government funds community housing but requires applicants to prove their current housing is unsuitable (QLD Govt, 2014). There is no mention disabilities in the application but Pave the Way, a non-profit group focused on future planning, recommends the applicant stress to the housing department that the individual is living with elderly parents (Pave the Way, 2014).

**The current supports for families with an ADD**

Australia has recognized the value and sacrifices of caregivers.

The Commonwealth dispenses the Carer Payment and the Carer Allowance to caregivers of adults with a disability. These payments recognize the caregiver may have relinquished some or all of their employment opportunity in order to provide unpaid caregiving and also recognizes parents have saved public funds (Allen Consulting Group, 2009). In 2014 under the Carer Payment, a care-giver can apply for and receive a maximum of AU$776.70 every two weeks (AU$1,682 per month) for a single caregiver or a maximum of AU$1,171 (AU$2,527 per month) for a couple providing care to a person with an eligible disability (HS, 2014). The amount received is income and asset tested. The Carer Allowance is an extra payment for caregivers who are providing care for person with a severe disability as determined by the Adult Disability Assessment Determination test. The Carer Allowance is AU$121.70 every two weeks (AU$263.68 per month) and is not means or asset tested (HS, 2014).

Australia has passed the **Carer Recognition Act 2010** as a step in the National Carer Strategy to support care-givers (DSS, 2010).

The Australian government also supports respite services through the Home and Community Care program and the National Respite for Carers program (Allen Consulting Group, 2009). The government-run Commonwealth Respite and Carelink centers also provides information on respite as well as other disability services (Allen Consulting Group, 2009).

The Older Carer Initiative is a program in Queensland focused on aging families co-residing with an ADD. The program provides extra respite to carers who are 65 years or older (50 years or older for Indigenous carers) who are living with and caring for a person disabled before the age of 65 years (DCCSDS, 2014). The respite can be obtained through selected service providers or though government-run respite centres
Families who use this program also receive counseling on future planning with regards to future housing (DCCSDS, 2014).

**Future planning in the political/social agenda**

Government awareness and stance on future planning. Australia has been proactive on future planning through research, providing information to parents and the creation of the special disability trust.

The government has undertaken several consultations with advocacy organizations and with parents to examine the issues within future planning. The report, *Succession Planning for Carers; Report on Consultations, January 2007* identified possible barriers to future planning (N-Carta Group, 2007) and in 2009, the government report *International Review of Future Planning Options* examined other countries for policies that could be adapted to Australia (Allen Consulting Group, 2009). Yet, five years later, in newspaper articles, older parents are often described as “struggling” with caregiving and needing more support from the government (Copland, 2012; Visentin, 2014). In one study, only 10 percent of parents over the age of 60 years had started future planning arrangements (Visentin, 2014).

The current government policy focuses on financial planning by the individual and the family. Future Planning is listed on the DSS webpage Programs & Services. Two booklets, one dedicated to Special Disability Trusts, and the other to estate planning are offered for free download.

The Queensland state government promotes future planning on its government website under the categories Support for Adults and Support for families, carers and friends. The government provides a link to the Commonwealth booklet on Special Disability Trusts and a booklet produced by a non-profit organization called Pave the Way (QLD Govt, 2014). Pave the Way provides workshops and information on succession planning throughout Queensland with an emphasis on building support circles in addition to will, trusts and special trusts (Ward, 2014).

Special Disability Trusts (SDT) gives families or friends the ability to create funding and/or manage assets for an individual with a disability without interfering with the DSP (Allen Consulting Group, 2009; DSS, 2015). Currently, up to AU$626,000 plus the residential home can be held in a SDT without affecting DSP income (DSS, 2015). The beneficiary of the trust must be assessed as being severely disabled. The trust must benefit the person by providing the means for accommodation, medical aids and care, along with a discretionary amount of AU$11,000 for items such as food, recreation, insurance and clothing (DSS, 2015). Setting up a SDT is daunting; legal and financial advice is recommended in selecting assets for the trust and choosing a trustee (DSS, 2015).

Parents feel the current policy focuses too heavily on their personal financial support and personal support arrangements for future planning while the government steps back from promising any support (N-Carta Group, 2007).
Innovative or unique policies aimed at future planning

Through the Department of Communities, Child Safety and Disability services, the Queensland government is conducting the Elderly Parent Carer Innovation Trial (EPCIT) at a cost of AU$15 million over 3 years (DCCSDS, 2014). EPCIT provides capital grants for innovative projects addressing housing/accommodation for adults with a disability who are co-residing with parents who are 60 years old and older. Successful proposals selected from calls to public tender and must be unique from other models on trial. Other criteria for proposals are: the organization must provide its own funds to the project, the project must not require new support funding, and the grant monies are subject to a mortgage that can be recalled if the project does not provide housing over the long run to the eligible population (Clerke, 2015). One of the underlying values of EPCIT is to allow the person with a disability to live as independently as possible and prepare for the time that the parents will no longer be able to provide caregiving. In some cases, parents may be ‘just down the road’, but two innovative housing arrangements are: 1) a 2 or 3 bedroom unit where both parents and person with a disability reside and 2) 2 units next to each other where one is occupied by the person with a disability and the other is occupied by the parents (Clerke, 2015).

EPCIT was a response to the lack of housing options for aging families co-residing with an adult child with a disability (Clerke, 2015). EPCIT criteria were set up by roundtable meetings of interested stakeholders who first met in 2012. By 2013, the first tender call-out was announced (Clerke, 2015). As of late fall 2014, 61 adults had been placed at a cost of AU$7.8 million (DCCSDS, 2014). The successful organization determines the applicants who receive the housing or, less commonly, families are from the Register of Needs. The rent will vary from project to project but typically is a percentage of the DSP. However there are many variations including the option to buy, the option rent-to-own, and cases where a multi-unit building may offer a small quantity of units for rent at market rates to off-set the costs of the rents for units accommodating people with disabilities (Clerke, 2015). EPCIT addresses parental concerns on planning for accommodation. Parents perceive the lack of accommodation options as a barrier to future planning and a source of great stress (Visentin, 2014). Parents want a ‘home’ that suits their child, a residence that is in the local area allowing the individual’s needs to be met (N-Carta Group, 2007). Parents have criticized the government for offering a very limited selection of housing and not increasing the number of residences available especially small-scale congregate housing (N-Carta Group, 2007).
Appendix L.

Documents and webpages for Washington study

<table>
<thead>
<tr>
<th>Website and webpages</th>
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<tbody>
<tr>
<td><a href="http://www.acl.gov/Programs/AIDD/DD_History/index.aspx">http://www.acl.gov/Programs/AIDD/DD_History/index.aspx</a></td>
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<tr>
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<td><a href="http://www.ddlot.org/">http://www.ddlot.org/</a></td>
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<tr>
<td><a href="http://www.acl.gov/Programs/AIDD/DDA_BOR_ACT_2000/p7_titleII.aspx">http://www.acl.gov/Programs/AIDD/DDA_BOR_ACT_2000/p7_titleII.aspx</a></td>
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<tr>
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<tr>
<th>Documents</th>
<th>Webpages</th>
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Appendix M.

Case Study: Washington State, USA

Demographics and government structure

<table>
<thead>
<tr>
<th>Category</th>
<th>Statistic</th>
</tr>
</thead>
<tbody>
<tr>
<td>Population of Washington State</td>
<td>6.7 million in 2010 (USCB, 2014)</td>
</tr>
<tr>
<td>Percentage of all population over 65</td>
<td>13.6% (USCB, 2014)</td>
</tr>
<tr>
<td>Population of ADDs</td>
<td>107,000 (State of States, 2011)</td>
</tr>
<tr>
<td>Annual median income</td>
<td>US$59,478 (USCB, 2014)</td>
</tr>
<tr>
<td>Type of government</td>
<td>Federalism, State government have powers over health and social systems, strong division of powers but Title XIX – Grants to States for Medical Assistance allows for federal funds and control in state services</td>
</tr>
<tr>
<td>Responsibility for ADDs</td>
<td>Family with some support from the two levels of gov’t</td>
</tr>
</tbody>
</table>

The United States of America is a federal model where the states are given constitutional rights to education, health and local concerns plus residual powers while the federal government was given powers over nation-wise concerns. The division of powers is enforced between the two governments making it onerous to develop nation-wide programs where the state governments have jurisdiction. US health and social systems are very different for Australia and Canada (Williamson & Perkins, 2014). Many of the laws governing programs are designed to fit two opposing demands: the state’s demand to allow as little federal government intrusion as possible and the federal government’s demand to demand accountability for the program money. This affects social programs. An example is Title XIX – Grants to States for Medical Assistance where Medicaid, a federal program, was established to provide funding for medical services for those who could not afford to pay (Healthinfolaw, 2011). If the states choose to participate, and thus benefit their residents, there are strict guidelines on how the funds are distributed. At the time Medicaid was written in 1965, it was common practice to institutionalize people with developmental disabilities and the act was written to pay for that service (Healthinfolaw, 2011).

Current support for persons with developmental disabilities

The supports for ADDs is complex and a combination of federal, state, charity and private services (Parish & Lutwick, 2005). Families provide most of the caregiving for person with a developmental disability (State of States, 2011) and the government-provided support is very limited (Allen Consulting Group, 2009). The United States government signed the UN Convention on the Rights of Persons with Disabilities on July 2009 but the Senate did not ratified the agreement (The Arc, 2012). The federal
government acknowledges people with developmental disabilities and the impact aging is having on this segment of the population.

**Income support from government**

Federal funding for persons with a disability is paid out through Supplemental Security Income (SSI) benefits through social security. Currently, a maximum of US$721 per month plus a state administered supplement is paid to qualified for SSI (SS, 2014). However SSI can be reduced by any amount of earned income, including the family income and the maximum value for assets is US$2,000 for an individual (SS, n.d.). The federal US government does not directly pay social welfare funds to individuals but funnels the funds through each state. An individual who is eligible for SSI may also apply for Supplemental Nutrition Assistance Program and Medicaid (SS, n.d.). States boost the SSI by adding the State Supplement Program and this amount varied from state to state.

The state dispenses the financial support in the form of the State Supplement program (SSP) as required by Title XIX. The amount of paid out is provided as a cash benefit and SSP varies depending on the individual but the most commonly reported annual amount is US$900 per year (Elrod & Davis, 2014). The cash is used to pay for transportation, recreation, clothing, respite care and, in some cases, food and living expenses. Most families reported having to spend another US$1,000 a year for out-of-pocket expenses (Elrod & Davis, 2014).

**Housing and service supports**

Home and Community-Based Services (HCBS) waivers allow the state to use Medicaid funds meant for institutions-based services for community based services for people with a developmental disability (Williamson & Perkins, 2014). The federal government reimburses each state between 50 to 77 percent for Medicaid costs spent on persons with a developmental disability (Parish & Lutwick, 2005). There are five types of HCBS waivers available to all ages of individuals with a developmental disability in Washington: Basic, Basic Plus, Core, Community Protection and CIIBS. However, Washington has capped the number of people in HCBS waivers in order to give more funds to those remaining in the program. In effect, this has created have and have-nots in the population with developmental disabilities.

According to 2012 data, 11,480 individuals were on waivers with annual amounts ranging from $9,805 for community protection to $1,562 for the basic waiver (Rolfe, 2012). The State of States reports US$820 million or 81% of total state spending on programs and services for developmental disabilities is sourced from a Medicaid program (State of States, 2011). The system is crisis driven (Rolfe, 2012).

The Developmental Disabilities Administration (DDA), part of the Washington State Department of Social and Health Services (DSH), manages services for ADDs. A developmental disability must be established by the state in order for the individual to be eligible for funding or services (Rolfe, 2012). Funding for services is provided contingent on three factors: assessment of needs level, an individual support plan (DDA, n.d.) and whether there is any capacity in the program. Demand is outstripping the funding for services; waitlists are common and only the Residential Habilitation Center and Medicaid

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Personal Care Services are guaranteed if a person is deemed developmentally disabled (Rolfe, 2012).

In 2012, out of the estimated 82,000 individuals eligible for DDA services, only 26,240 were receiving services (Rolfe, 2012). Once funding has been obtained, the DDA is joined by the Aging and Long-Term Support Agency, the Home Care Referral Registry and county’s employment and day services in managing the services provided to the ADD (DDA, n.d.).

Community residential services are funded by the state and divided into facility-based (group homes and residential care) and non-facility-based (supported living or home share, family home and tenant support).

Nearly 75,000 or 70% of individuals with a developmental disability live with a family caregiver with the remaining 30% are equally split between residential care and living alone or with a roommate. Further, it is estimate that 17,000 of those living at home are with caregivers who are older than 60 years (State of States, 2011).

The complexity of the disability system is challenging for families to navigate and, as a result, there are strong advocacy groups in Washington. The largest organization is the Washington chapter of Arc and its affiliated county organizations. The Arc is a nationwide organization that provides lobbying, workshops, information to parents and networking (ARC, n.d.). Advocacy for families and for individuals with a developmental disability is also provided by the Washington State Developmental Disability Council whose members are appointed by the Governor of Washington (DCC, n.d.).

**The current supports for families with an ADD**

Individual & Family Supports funding covers respite and for parents and family caring for a person with a developmental disability but is primarily used as a crisis fund (ARC, 2013).

Family Caregiver Support Program of Washington State is a policy from the Aging and Long-Term Support Administration and operated by the local chapters of the Area Agency on Aging (DSHS, n.d.).

**Future planning in the political/social agenda**

Developmental Disabilities Life Opportunity Trust (DDLOT) is a Washington State initiative that allows families to set up assets that would not interfere with an individual’s SSP or HCBS funding (DDLOT, 2011). Started in 1999, there are currently 1,600 DDLOT trusts. Each trust requires a US$600 enrollment fee which is matched by state funds and to maintain the trust the family or recipient is required to deposit $25 a month (DDLOT, 2011). Once the trust is vested, up to six free withdrawals a year can be processed and the money can be spent on any expenses except for food and housing.

The ARC, a national advocacy group for people with a developmental disability, has published booklets and created webinars on future planning for the past decade.

Within the *Developmental Disabilities Assistance and Bill of Rights Act of 2000* is section 202, a4 which acknowledges the aging of care givers will increase the demand for disability services (US Govt, 2000). The Act goes on to proclaim the government will
support families to raise their children at home by increasing the supports to the home. In section 101, the following quote serves as a reminder that future planning has been a concern for well over a decade; “many service delivery systems and communities are not prepared to meet the impending needs of the 479,862 adults with developmental disabilities who are living at home with parents who are 60 years old or older and who serve as the primary caregivers of the adults” (US Govt, 2000, p. a.11).

**Innovative or unique policies aimed at future planning**

The Arc has implemented a website, Center for Future Planning, dedicated to future planning. The website, which was launched in December 2014, caters to parents, siblings, friends and professionals. Different webpages list topics for discussion, resources, and examples (ARC, n.d.).