The "Hows" and "Whys" of Parental Future Planning for Adults with Intellectual Disabilities: An Interpretive Description Inquiry

by

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B.A., Acadia University, 2006
M.Sc, University of Victoria, 2009

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Supervisory Committee

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Abstract

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This study focuses on parental future planning for adults with intellectual disabilities. In recent years, the need for parents to engage in future planning for their offspring with intellectual disabilities has been increasingly emphasized. Within the literature, a number of approaches to future planning have been identified, including both formalized approaches (i.e., creating clear, explicit, and largely unchanging plans for the future of the individual with an intellectual disability) and more informal approaches (i.e., designating a person or a group of people to oversee the well-being of the individual with an intellectual disability without necessarily providing specific guidelines relating to the individual's future care). Despite growing understanding that parents may approach developing future plans in different ways, to date, research on future planning has largely been focused on exploring formalized, concrete approaches to future planning. Using an Interpretive Description methodology, in which semi-structured interviews were conducted with 28 parents of adults with intellectual disabilities, this study sought to gain a greater understanding of parental future planning in real life practice in the province of British Columbia. Results revealed that while the parents in this study often utilized several future planning approaches -- both formal and informal -- when engaged in planning, they could be classified into two broad categories: Concrete Planners and Informal Planners. In addition, the results of this study also highlight key factors that may distinguish between parents who plan more formally and parents who plan more informally. Overall, these result highlight important avenues for future research and policy and practice; which, ultimately, may lead to important changes regarding how best to support aging parents of adult children with intellectual disabilities as they face the challenging task of planning for the post-parental care phase of their adult child's life.

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CHAPTER 1: INTRODUCTION

In recent years, greater attention has been paid to aging family caregivers of adults with intellectual disabilities. One area of particular interest has been the way in which parental caregivers plan for the future of their adult children with intellectual disabilities when these parental caregivers are, themselves, no longer able to provide care.

While research in the area of intellectual disabilities overwhelmingly emphasizes the importance of parental caregivers planning for the future of their children (Heller & Caldwell, 2006), serious gaps still remain with respect to our understanding of the future planning process. Specifically, a number of different approaches to future planning have been identified in the literature, including both formalized approaches (i.e., creating clear, explicit, and largely unchanging plans for the future of the individual with an intellectual disability) and more informal approaches (i.e., designating a person or a group of people to oversee the well-being of the individual with an intellectual disability without necessarily providing specific guidelines relating to the individual's future care). However, despite growing understanding that parents may approach developing future plans in different ways, to date, research on future planning has largely been focused on exploring formalized, concrete approaches to future planning (Bigby, 2000, 2004).

This primary focus on formalized future planning is problematic, as research suggests that the majority of parents who plan for their adult children with intellectual disabilities may actually be engaging in more informal planning approaches (Bigby, 1996). With this in mind, it appears that there is still very limited understanding regarding *how* parents actually plan for their adult sons and daughters with intellectual disabilities in real-life practice.

This unnecessarily narrowed focus on concretized approaches to future planning also means that little is understood regarding *why* parents choose to plan in a given manner. While past research has sought to explore factors that distinguish between parents who develop concrete future plans (particularly relating to future housing needs) and parents who do not develop any future plans (Essex et al., 1997; Freedman et al., 1997; Heller & Factor, 1988, 1991; Smith et al, 1995), almost no research has examined the factors that may distinguish between parents who develop future plans for their adult children with intellectual disabilities in different ways.

In light of current gaps in the literature regarding parental future planning for adults with intellectual disabilities, research espousing a broader, more inclusive definition of future planning is clearly needed. Such research will help to shed light on the wide range of ways in which parents approach the future planning process; and will lend greater awareness to, and appreciation for, the more informal -- but still valuable – planning that many parents may be engaging in when trying to prepare for the post-parental care phase of the lives of their children with intellectual disabilities (Bigby, 1996, 2000).

Purpose of Inquiry

The purpose of this inquiry was to gain a greater understanding of the phenomenon of parental future planning for adults with intellectual disabilities – both from the perspective of *how* parents plan in real-life practice, and *why* parents plan for their adult children in a given manner. Within the literature review (see Chapter 2: Literature Review), three previously identified approaches to future planning (i.e., concretized, detail-oriented planning; key person succession planning; social network planning) are presented as launching off points for asking parents about their respective future plans and about what informed their decisions to plan in particular ways. While using these three identified approaches served as a useful starting point for this inquiry, this research also sought to uncover forms of future planning, or ways of conceptualizing parental future planning, that may have fallen outside these specified approaches to future planning.

Significance of Study

This study impacts the field of disability studies, policy-makers for individuals with intellectual disabilities, service providers, and families of individuals with intellectual disabilities. The results of this research provide a foundation from which parental future planners for adults with intellectual disabilities may be conceptualized in the future; thereby, helping to provide a "sense-making structure" (Thorne et al., 2004) for how to better understand the variations in how parents engage in future planning. In addition, through this inquiry, several avenues were highlighted for future exploration and development which, ultimately, may lead to important changes regarding how best to support aging parents and adult children with intellectual disabilities as they face the challenging task of planning for the post-parental care phase of their adult child's life.

A key finding of this research is that parental planners can be classified into two broad categories – 1) Concrete Planners, and 2) Informal Planners. In addition, findings from this study suggest that there are key factors that may distinguish between parents who plan more formally and parents who plan more informally. This increased understanding of how to conceptualize parental planners may be drawn on when attempting to design effective interventions that foster the unique needs of parental future planners for adults with intellectual disabilities. For example, some parental future planners might desire intervention strategies focused on helping them develop concretized, detail-oriented future plans. In contrast, other parental planners might be most receptive to future planning interventions that focus on more informal approaches to future planning (i.e., fostering a strong social support network, having discussions about the future with close others). Having a more nuanced approach to future planning interventions might lessen the likelihood of parents feeling that their needs and values are not adequately reflected in these intervention strategies; which, ultimately stands the risk of alienating parents from the future planning process.

With an increased understanding of the factors that may be associated with different types of planning, it may also be possible to develop intervention strategies that support a particular approach to future planning. For example, the findings from this research suggest that higher degree of engagement with the formal service system may be associated with more formalized approaches to planning. Therefore, if the goal is to have parents create formalized future plans, service providers and policy makers might focus on providing parents ample opportunities to engage with the formal service system (e.g., day program, respite care, community inclusion activities, etc.) prior to parents beginning the planning process.

Findings from this study will be shared with other families, policy makers, and service providers in the hopes of increasing the dialogue around the future planning process. If parents have a better understanding of the different forms that future planning for individuals with intellectual disability can take, they may be more inclined to engage in the future planning process for their adult children with special needs. If policy makers and service providers are more aware of how parents are planning for their adult children in real-life practice, and if they have some insight into the factors associated with different forms of planning, then they may be able to develop more effective ways of supporting parents and families through the future planning process.

Qualitative Approach Underlying Inquiry

An interpretive descriptive approach (Thorne, Reimer Kirkham, & MacDonald-Emes, 1997, Thorne, 2008) was utilized as the orienting framework within which this inquiry was conducted. Interpretive description is an approach to knowledge generation that “straddles the chasm between objective neutrality and abject theorizing” (Thorne, 2008, p. 26), with the ultimate goal of illuminating the characteristics, patterns, and structure of the phenomenon under investigation in some theoretically useful manner. As noted by its creator, this approach arose from a need for an applied qualitative research approach that would generate better understanding of complex experiential clinical phenomena within professional disciplines that are concerned with applied knowledge or questions “from the field”

(Thorne, 2008, p. 27). With this in mind, Thorne argues that an interpretive descriptive approach to research requires an integrity of purpose that is derived from two key sources – 1) an actual practice goal, and 2) an understanding of what is and is not known about the phenomenon of interest based on the available empirical evidence (Thorne, 2008, p. 35). Given the applied nature of the present inquiry (i.e., seeking to gain a richer understanding of parental future planning in real-life practice), and the ability for the information obtained from this investigation to have implications for intervention strategies targeting future planning, it was felt that an interpretive descriptive approach was particularly well suited to this research.

Thorne (2008) emphasizes that while techniques for data collection and analysis may vary within studies employing an interpretive descriptive approach, the foundation in the interpretive naturalistic tradition helps to distinguish these studies from those that are simply engaged in "method slurring" (Thorne et al., 2004, p. 4). With this in mind, interpretive description does not provide a prescriptive, circumscribed sequence of steps that is characteristic of many other qualitative traditions (i.e., ethnography, grounded theory, phenomenology) (Thorne, 2008). Instead, Thorne (2008) argues that interpretive description offers a "coherent methodological framework within which a fairly wide range of options for design decisions can be enacted and justified" (p. 75).

Within the current inquiry, given the complexity of the phenomenon of interest (i.e., parental future planning for adults with intellectual disabilities), in-depth interviews with parents who had adult children with intellectual disabilities were conducted as a means of capturing important themes and patterns related to the future planning process. Through a process of inductive analysis, the researcher then developed a coherent conceptual description of future planning that furthers our understanding of this phenomenon, and could potentially be utilized to inform interventional strategies aimed at facilitating parental future planning. For more detail on interpretive description and on how it guided design decisions within the current project, see Chapter 3: Method.

Positioning of Researcher within Inquiry

As noted by Thorne and colleagues (Thorne et al., 2004), "it is the researcher who ultimately determines what constitutes data, which data arise to relevance, how the final conceptualizations portraying those data will be structured, and which vehicles will be used to disseminate the findings" (p. 12). With this in mind, Thorne et al. (2004) recommend that the positioning of the researcher within the research process be made transparent. In so doing, Thorne (2008) suggests that the researcher make explicit any ideas, thoughts, perspectives, or personal experiences that have the potential to influence the "angle of vision" (p. 72) that the researcher brings to the study.

In reflecting on my role in shaping this research, I believe it is important to note that I worked for several years with adults with intellectual disabilities, particularly in the capacity of conducting assessments to aid in determining need for support services. I also have several years of volunteer experience with adults with intellectual disabilities, which focused on providing community inclusion activities for this population. In these capacities, I have witnessed the important role that parental caregivers can play in the lives of their children, both in the present and in the future when they are no longer able to provide care themselves. Through these experiences, I have also gained an appreciation for the crucial function that a strong social support network can serve in the lives of individuals with intellectual disabilities and in the lives of their primary caregivers (e.g., parents, typically-abled siblings, other family members).

Through my work and volunteer experiences, I have witnessed the detrimental impact that not having adequate future plans in place can have on the adult with an intellectual disability, the larger family system, and the formal service system. I have also witnessed the myriad forms that future planning can take, and I am of the opinion that no particular approach to future planning is necessarily the "best" approach. Instead, I believe it is of vital importance that there is a good "fit" between the future plans and the individuals involved in these plans (e.g., the parent(s), the individual with an intellectual disability, other family members, etc.).

In conducting this research project, I sought to remain cognizant of the potential for my beliefs to influence the focus of this inquiry. At all times, my goal in this research was to develop an interpretive account of parental future planning that was grounded in the data, as opposed to simply being a reflection of my own thoughts, beliefs, and perspectives on the topic of future planning.

Final Comments

In keeping with an interpretive descriptive approach, which calls for an inquiry to be thoroughly grounded within the existing empirical evidence related to the phenomenon under investigation, the following chapter is a review of the literature on future planning. This review provides the reader with a clear understanding of what is, and what is not, currently known about how and why parents future plan for their adult children with intellectual disabilities. Through this literature review, a clear case is made for why further research focused on gaining a greater understanding of parental future planning – particularly aimed at addressing *how* parents future plan, and *why* parents future plan in a given manner – is still needed; thereby, helping to “scaffold” the current inquiry (Thorne, 2008, p. 55).

CHAPTER 2: REVIEW OF LITERATURE

Of relevance to the current inquiry, the following chapter: 1) provides an overview of relevant definitions and demographics related to individuals with intellectual disabilities and their family caregivers; 2) discusses the research related to the future planning process in general (i.e., degree of future planning, barriers to future planning, correlates of future planning); and 3) outlines different future planning approaches, and discusses relevant research related to the selection of particular planning approaches. With this review of the literature acting as a "scaffold" (Thorne, 2008, p. 55), this chapter closes with a description of the purpose and specific research questions that guided this research.

Part I: Definitions and Demographics

Definitions

<u>Intellectual disability.</u> An intellectual disability (ID) is a disability characterized by significant limitations both in intellectual functioning and in adaptive behaviours, which extends to a variety of social and practical skills. The condition is first evident in childhood, and is generally considered to be lifelong (American Association of Intellectual and Developmental Disabilities, 2011). As noted by Jokinen (2008), a variety of other definitions for "intellectual disability" are used by different governments and organizations, which, though similar in some respects, also have notable differences. Primarily, these definitions serve to set inclusion/exclusion criteria for services.

Within the literature, various terms are used interchangeably with "intellectual disability," such as "developmental disability" in Canada, "mental retardation" in the United States, and "learning disability" the United Kingdom (Jokinen, 2008). "Developmental disability" - a commonly used term in Canada - encompasses a variety of conditions in which limitations in intellectual functioning may or may not be present (e.g., cerebral palsy, epilepsy, visual impairment, etc.). With this in mind, the term "intellectual disability" was used throughout this research in order to more accurately define the focus of this inquiry.

Demographics

Prevalence of adults with an intellectual disability. As noted by Jokinen (2008), determining the "true" numbers of adults with an intellectual disability is challenging. The overall prevalence rate for intellectual disability is 1%-3% (World Health Organization, 2001); however, this rate is generally applied to child populations and not across the lifespan. With this in mind, different methods have been used to estimate the number of adults with an intellectual disability (i.e., figures from general registries for disability services, statistics generated from national surveys). However, the reliability and accuracy of these estimates is questionable, given that findings can be influenced by such things as variations in operational definitions and classifications of intellectual disability, and by sample populations (i.e., relying on registries of individuals in receipt of, or requesting, formal service does not account for individuals who are unknown to the service system) (Jokinen, 2008).

Perhaps due to these reliability and accuracy issues, there has been wide variability in reported prevalence rates. For example, Beange and Taplin (1996), an Australian study of 20-50 year olds living in the Northern suburbs of Sydney, found an overall prevalence of 3.31/1000. In a similar vein, McGrother et al. (2002), in investigating prevalence rates of South Asian and Caucasian adults in the United Kingdom, reported a rate of 3.2/1000 for South Asians and 3.62/1000 for Caucasians. Other studies have reported higher prevalence rates. For example, Larson et al., (2001) reported a prevalence estimate in the United States of 7.8/1000, and the authors note that this figure excludes institutionalized people.

Despite the lack of consensus in reported prevalence rates, there is agreement in the literature that the population of adults with intellectual disabilities is increasing and will continue to grow as the "baby boom" generation ages (Bigby, 2004; Heller, Janicki, Hammel, & Factor, 2002). Additionally, as noted by Jokinen (2008), adults who are currently unknown to the formal service system are likely to become increasingly apparent as parental caregivers age and require greater formal supports and intervention.

Life expectancy. The life expectancy of adults with intellectual disabilities has increased dramatically over the past several decades (Emerson, Hatton, & Robertson, 2012; Janicki, Dalton, Henderson, & Davidson, 1999). By way of an example, for an institution-based population of people with intellectual disabilities in 1931, the average life expectancy was 14.9 years for males and 22.0 years for females (Carter & Jancar, 1983). More recently, Bittles, Sullivan, Petterson and Hussain (2002) found that the mean age at death ranged from late fifties for those with more severe disabilities or Down Syndrome to 71 years of age for adults with mild to moderate intellectual disabilities. It has also been noted elsewhere (Gilbert, Lankshear, & Petersen, 2007; Janicki et al., 1999) that a significant proportion of adults with intellectual disabilities can now expect to live to ages expected within the general population.

Number of adults with intellectual disabilities residing with family. Similar to the difficulties related to determining the prevalence of adults with intellectual disabilities, it is also challenging to estimate the number of adults with intellectual disabilities who reside with family members. Perhaps the largest obstacle to gaining an understanding of the extent of in-home care provision for this population relates to what the literature refers to as “hidden populations” (Jokinen, 2008). For example, in one study it was found that a significant proportion (i.e., almost 50%) of older-aged families who were providing in-home care to adults with an intellectual disability were unknown to disability services (Janicki, McCallion, Force, Bishop, & LePore, 1998).

Despite these reservations, the estimate that between 50 and 60 percent of people with intellectual disabilities live with family caregivers has been widely accepted (Braddock, Emerson, Felce, & Stancliffe, 2001; King & Harker, 2000; Prouty, Alba, & Lakin, 2008). As noted by Heller and Caldwell (2006), the number of family caregivers providing in-home care is increasing, and is expected to continue increasing for the next several decades, due to such things as the dramatically increased life expectancy of individuals with intellectual disabilities and to long waiting lists for residential services. Importantly, a substantial body of research suggests that this growing number of in-home family caregivers includes both parents and typically-abled siblings (Heller & Arnold, 2010); these siblings frequently act as successors for their parents when their parents relinquish their primary caregiving responsibilities for the individual with an intellectual disability (Bigby, 2000; Heller & Kramer, 2006; Heller & Kramer, 2009).

Length of care provision. As noted by Haley and Perkins (2004), in light of the markedly increased life expectancy of individuals with intellectual disabilities, caregiving for a child with an intellectual disability is now a prolonged endeavor that can last for 60 years or more. For many of these caregivers, their role of providing care only ends with their own death or when they are no longer able to provide care due to age-related health declines. With this in mind, it is not surprising that for the majority of these caregivers, providing care becomes a lifelong career.

The length of care provision required of parental caregivers to adults with intellectual disabilities is particularly impressive when contrasted with the average length of time that other caregiver groups provide care. For example, caregivers providing assistance to older adults with a chronic illness provide, on average, 4.5 years of care (Haley & Perkins, 2004).

Part II: Future Planning Research

The need for older-aged parental caregivers to engage in future planning for their relatives with intellectual disabilities is a dominant theme within the literature. In the broadest of definitions, future planning can relate to any or all of the following facets: addressing future living arrangements, guardianship and other less restrictive alternatives, financial planning, future vocational and recreational desires, and general lifestyle choices (Heller & Caldwell, 2006). Emphasis is placed on the future planning process because it is believed that without adequate plans and supports in place, individuals with intellectual disabilities can face the unfortunate situation of emergency placements in inappropriate settings, and inadequate financial and legal safeguards when primary caregivers can no longer provide care (Heller & Schindler, 2009).

Unplanned transitions can be very detrimental for individuals with intellectual disabilities, and are associated with depression, dementia, and reduced coping capacity (Botsford & Rule, 2004). Moreover, as noted by Heller (2000), a lack of adequate plans can also have serious repercussions for other family members, particularly for typically-abled siblings who often assume the role of post-parental caregiver.

The following sections will provide an overview of the research relating to: 1) the degree to which caregivers engage in future planning, 2) the barriers to future planning, and 3) the factors associated with future planning. Prior to this discussion though, it should be noted that researchers have generally defined evidence of future planning as having a formal plan with respect to residential care. Obviously, this is a narrow, and very concrete, conceptualization of future planning, which fails to consider other factors of relevance to the planning process (See Part III: Future Planning Approaches for more detail). With this in mind, the applicability of these research findings to less formal future planning approaches (i.e., key person succession plans, social network plans) is questionable.

Degree of future planning

A substantial portion of older caregivers has not created formal plans for the future of their care-recipients. For example, Kaufman, Adams, and Campbell (1991) found that 51% of their sample had no concrete plans for the future, and a similar figure was noted by Freedman, Krauss, and Seltzer (1997). Prosser (1997) asserted that as many as 71% of caregivers have not made future residential plans. As noted by Heller and Factor (1991), parental caregivers are generally more likely to make legal and financial plans for their care-recipients, as opposed to residential plans. For example, Heller and Factor (1991) found that less than one third of the family caregivers interviewed had made any concrete future living arrangements for the adult offspring they were supporting. In contrast, over two thirds of these caregivers had made financial arrangements for their children. Overall, research suggests that 55 to 75% of familial caregivers do not have a formal residential plan for their child's late-life care (Krauss & Seltzer, 1995). Current research (i.e., Heller & Schindler, 2009) suggests that parental caregivers' low rates of concrete future planning – particularly in the area of future residential needs -- have continued to be an area of significant concern.

Limiting the definition of future planning to solely include planning for residential care is likely to yield an unnecessarily grim picture. For example, Bigby (1996) found that by expanding the definition of future planning to include less comprehensive, and more flexible plans (i.e. "Plans were defined as ideas or arrangements made by parents that concerned the care of their adult child with intellectual disability when parents had died, were incapacitated, or chose to cease being the primary carer," p. 300), the vast majority of parental caregivers had engaged in planning for the future care of their care-recipient with an intellectual disability. Specifically, these findings highlight the fact that plans for the future may often remain at the informal level, never developing into the comprehensive, concrete plans frequently suggested as necessary in the literature (Heller & Factor, 1991; Smith, Tobin, & Fullmer, 1995). Importantly, as will be discussed in more detail below (See Part III: Future Planning Approaches), informally-based plans may still be effective in facilitating transition from parental care, and preventing urgent requests for services (Bigby, Bowers, & Webber, 2011).

Further confounding the ability to assess degree of planning is the fact that plans and expectations may change over time. For example, Grant (1988) found that during a 2-year period, more than half the parental caregivers in his study changed their preference with respect to the future care of their child with an intellectual disability. Moreover, as note by Jokinen, Janicki, Hogan, and Force (2012), even in the face of well-articulated concrete plans, occasionally unexpected medical or other significant crises can lead to plans needing to be changed rapidly. Thus, even the relatively small portion of caregivers who have engaged in formal planning may not actually act on the plans they have developed.

Barriers to future planning

Given the findings of limited formal future planning among familial caregivers for their sons and daughters with intellectual disabilities, researchers have sought to identify barriers related to engaging in this process. A study by Bowey and McGlaughlin (2007) comprehensively sheds light on the barriers to formal future planning. Specifically, through a series of interviews and questionnaires with older aged caregivers (70 years of age and over), the authors identified a number of barriers to the planning process including: a lack of awareness of the long timescales involved in securing appropriate housing; an element of denial about the inevitability of not being able to provide care indefinitely; the presence of two caregivers in the family home, leading caregivers to believe that plans are not currently necessary; the perception that engaging in future planning will lead to the caregiver having to give up their caregiving role before they feel the need; opposition on the part of the care-recipient relating to making future plans and/or moving elsewhere; and previous negative experiences with the formal service system.

In addition to the barriers highlighted by Bowey and McGlaughlin (2007), it has also been noted that tremendous residential waiting lists may inhibit caregivers from future planning, as they may have low expectations of securing a desirable residential placement for their care-recipient even with the appropriate plans in place (Freedman et al., 1997). Moreover, Freedman et al. suggest that for caregivers of individuals with more severe intellectual difficulties, their acute awareness of the constraints in service availability for individuals with such high needs may keep them from planning, as they perceive no desirable formal options available.

A lack of trust has also been noted as a barrier to the future planning process. In particular, it has been suggested that trust of professionals and of the service system may be a particularly salient issue for the current cohort of aging caregivers who have historically not received appropriate supports (Jokinen et al., 2012). Furthermore, many professionals continue to blame older caregivers for not fostering independence of individuals with intellectual disabilities and not making plans for the future (Davy & Haigh, 2007; Gilbert et al., 2007; Heller & Caldwell, 2006; McCallion & Tobin, 1995).

Interdependence of the caregiver and care-recipient has also been recognized as a potential barrier to future planning (Jokinen, 2006). Specifically, the relationship that exists between many older caregivers and the adults with intellectual disabilities for whom they provide care is increasingly seen as being mutually supportive, in which the caregiver not only supports the care-recipient but also is supported by the care-recipient. Beyond providing emotional support, affection, and companionship, the care-recipient may also aid the aging caregiver with tasks they find increasingly difficult to perform (e.g., simple housecleaning, running errands). With this in mind, caregivers may avoid planning for the future due to their own reliance on the care-recipient in their day-to-day life (Jokinen, 2006), and due to fears of the loneliness and isolation they may experience if the care-recipient moves elsewhere (Bowey & McGlaughlin, 2007).

Finally, a lack of information about available resources has also been identified as a salient barrier to future planning. Specifically, Jokinen et al. (2012) highlight the fact that while many parents may be aware of the need to develop plans – particularly with respect to their offspring's future residential needs - they often lack needed information.

Factors associated with future planning

Despite the reported high rates of non-engagement in future planning, some caregivers do, in fact, make formal plans, and past research has attempted to identify factors that are related to engaging in such planning. Unfortunately, much of this research is quite dated, and the results of these research efforts are somewhat inconsistent (Joffres, 2002). For example, one factor that has been posited as being associated with formalized future planning is informal support (i.e., support from family and friends). Both Heller and Factor (1991) and Essex et al. (1997) found that fewer informal supports predicted more formalized planning. The authors argued that parental caregivers with a higher degree of social support may believe that informal supports can assume responsibility for the care-recipient in the future, thereby decreasing the need for formalized plans**.** However, contradicting the findings of Heller and Factor and Essex et al., both Kaufman et al. (1991) and Smith et al. (1995) reported that higher levels of informal support were actually associated with increased planning.

Increased service utilization has also been suggested as a correlate of formalized future planning. In particular, Heller and Factor (1991) and Smith et al. (1995) found that the extent of residential planning was related to the use of such formal services as respite care and day programs. The authors suggested that it is possible that the use of such services may make families less wary of the service system in general, and may decrease their apprehensiveness towards existing residential care options. Subsequent research conducted by Freedman et al. (1997), however, found no association between formal service utilization and residential planning.

Regarding characteristics of the adult with an intellectual disability, Freedman et al. (1997) and Kaufman et al. (1991) found that parents of adult children with more severe intellectual impairments were less likely to make formalized residential plans than were parents of individuals with more mild impairments. The authors suggest that parents may perceive more variety in residential options for dependents with more capabilities and, thus, may be more willing to articulate plans. Again, other studies (Pruchno & Patrick, 1999) found no association between the ability level of the individual with an intellectual disability and planning behaviour.

Relating to family or parental characteristics associated with future planning, a number of researchers (Black, Molaison, & Smull, 1990; Heller & Factor, 1988; Sherman, 1988) have suggested that parental aging significantly increases the likelihood of formalized future planning. Other researchers (i.e., Freedman et al., 1997) though, have found no such association between parental age and planning behaviour. Results are also quite mixed regarding the association between familial socioeconomic status and future planning. For example, both Grant (1989) and Kaufman et al. (1991) found that higher income was associated with increased formalized planning; however, Freedman et al. (1997) did not find any association between income level of planning behaviour, and still other studies (Black, Cohn, Smull, & Crites, 1985; Black et al., 1990) actually found the reverse of Grant's and Kaufman et al.'s findings.

Marital status has also been suggested to be a correlate of formalized future planning. Specifically, Freedman et al. (1997) found that planning was more likely among mothers who are no longer married, as they may feel more pressure as single parents to articulate their expectations for their dependent offspring. This finding of marital status predicting future planning has never been confirmed by other studies that have included similar variables (Joffres, 2002). Finally, higher caregiver burden (Pruchno & Patrick, 1999) has also been suggested as being associated with an increased likelihood of caregivers making formalized future plans; again, other research involving similar variables (Freedman et al., 1997) has found no such association.

Clearly, there continues to be a lack of agreement in the literature regarding the true correlates of formalized future planning. Moreover, there is a veritable dearth of knowledge regarding the possible correlates of less formalized future planning behavior.

Part III: Future Planning Approaches

Although the need for families to engage in future planning is well-documented, the most effective ways for parents to engage in this process remains unclear (Heller, 2000). Within the literature, a few different parental approaches to future planning have been identified. At present, there is little understanding regarding why parental caregivers select one form of future planning, or a particular combination of future planning approaches, over another. Moreover, with a few notable exceptions, there has been scant empirical investigation conducted in order to evaluate the effectiveness of these different planning strategies (Heller, 2000), with a heavy reliance on the anecdotal reports of caregivers and service providers.

The following section will provide an overview of the three major future planning approaches – concretized, detail-oriented planning; key person succession planning; and social network planning. Where available, relevant research will be highlighted. This section will close with a discussion of the very little research available related to identifying the factors associated with selecting a particular future planning approach.

Concretized, detail-oriented planning

Traditionally, researchers and health practitioners have advocated for parental caregivers to develop comprehensive, concrete plans relating to the future care of their care-recipients with intellectual disabilities (Heller & Factor, 1991; Heller & Schindler, 2009; Smith et al., 1995). Such comprehensive plans, it is supposed, can avert the crisis of an ill-prepared transition from parental care, ensure longer term security and stability for the person with an intellectual disability, and can forecast future service demands (Heller & Factor, 1988; Kaufman et al., 1991).

From this detail-oriented perspective, the notion of planning is a straightforward endeavor: “Proper planning includes making financial and guardianship arrangements, and finding appropriate [residential] placements“ (Heller & Factor, 1988, p. 2). In the effort to avert crisis transitions from parental care, the creation of detailed residential plans is generally seen as being at the heart of this form of future planning (Bigby, 2000). These residential plans may involve a number of activities, including placing the care-recipient’s name on a waiting list, organizing his or her move to supported accommodation, and/or arranging support for continued living in the community (Bigby, 2000).

Given the strong support for concretized future planning within the academic and medical communities, efforts have been made to better support parents in engaging in this form of planning. For example, training workshops, seminars, and discussion groups have all been developed for the purpose of aiding parents in developing concretized, detail-oriented plans for their adult children with intellectual disabilities (Heller, 2000). In general, these concrete planning intervention strategies have been found to be somewhat effective in increasing parents' completion of important formalized future planning activities (i.e., taking action on residential planning, developing a special needs trust), in improving parents' awareness and knowledge of formal planning resources, and in fostering greater competence and confidence in parents' regarding their ability to plan for the future (Botsford & Role, 2004; Heller & Caldwell, 2006). Despite the possible utility of these concrete planning interventions, it should be noted that questions still remain as to whether these positive planning effects are maintained over time (i.e., whether parental caregivers continue to move forward in the planning process after the intervention), regarding the degree to which parents actually adhere to the plans they create during such interventions (Grant 1988), and regarding whether these interventions are equally effective for parents who are not already connected with the formal service system (i.e., these intervention studies have generally drawn their sample from disability-specific agencies and organizations).

As a final note, in discussing concretized, detail-oriented future planning, an issue that demands consideration is the appropriateness of parents formulating plans that resemble detailed blueprints for the future of their adult children with intellectual disabilities. Specifically, Grant (1988) suggests that contemporary ideologies and values reflected in the service system may challenge previously taken-for-granted rights of parents to decide the future pattern of care for their adult children. It is important to recognize that adults who make the transition from parental care in their 40s and 50s have perhaps 20 or 30 years of life ahead of them. Designing and implementing a plan to determine the course of their lives in the post-parental care phase is a very challenging task; many contingencies must be dealt with, particularly since this phase of the care-recipient's life may be characterized by instability and change (i.e., health status changes, development/decline in other skills, changes in social and service contexts, changes in organizational policies). Attempting to identify a plan, particularly one that involves a suitable and desired residential situation for the rest of the adult child's life, may not be realistic for some parental caregivers (Bigby, 2000, 2004) and may not be appropriate or desirable for the individual with an intellectual disability.

Key person succession plans

While future planning is often viewed as a straightforward series of arrangements relating to finances, guardianship, and place of residence, others conceptualize planning as a "complex dynamic process whereby plans must be sufficiently flexible and adaptable to meet the *changing* residential, financial, and legal requirements of an adult who may survive his or her parents by 30 or 40 years" (Bigby, 2000, p. 81). Proponents of more flexible, informal forms of future planning suggest that the goal of planning should not necessarily be to achieve a secure, permanent residential situation, but, instead, to ensure that family members remain involved with the person with intellectual disability and monitor the quality and appropriateness of services over time (Bigby, 2004; Seltzer & Seltzer, 1985).

In recognition of the precariousness of permanent plans, some researchers have begun to encourage more flexible, less formalized approaches to future planning (Bigby, 1996, 2000, 2004; Bigby et al., 2011; Jokinen, 2006). In particular, Bigby (1996, 2004) calls for "key person succession plans," which involve the planned transfer of responsibility for overseeing the well-being of the person with an intellectual disability to a nominated person – often a typically-abled sibling (Heller & Schindler, 2009). The responsibilities of nominated key people vary from situation to situation; however, their roles often involve such tasks as financial management, decision-making, negotiation, coordination, mediation with services, supervision, and sometimes primary care.

Importantly, key person succession plans are not necessarily created at the exclusion of other forms of future planning. Specifically, Bigby (2000) conceptualizes key person succession plans as potentially including both explicit key person succession plans and implicit key person succession plans.

Bigby (2000) explains that while both explicit and implicit key person succession plans involve the nomination of a key person to assume responsibility in over-seeing the well-being of the individual with an intellectual disability, explicit and implicit plans differ in their level of formality and structure. For example, explicit plans are discussed with the nominated person and/or written into a formal document (i.e., a representation agreement); such plans are frequently made in conjunction with other more detailed, concrete plans (i.e., residential plans, finanacial plans). In these instances, these concrete plans can offer a blueprint to nominated key persons, making their roles quite specific and prescribed.

In contrast, implicit key person succession plans are generally quite vague and “minimalist” in detail, and may not even be discussed with involved others. These sorts of plans are frequently created in the absence of other more concrete forms of planning. In such instances, the wide, open-ended brief of the nominated key person can compensate for the lack of more detailed forms of planning (Bigby, 2000). Regardless of these differences, at the heart of both types of plans remains the nominated key person who has ongoing involvement in the life of the person with the intellectual disability, with the ability to deal with unforeseen contingencies as they arise and the capacity to provide informal advocacy for the person with special needs.

This notion of there being a nominated key person when developing plans seems very apparent within the research that has focused on sibling caregivers for individuals with intellectual disabilities. Specifically, it appears that many parents envision a typically-abled offspring as assuming responsibility for the individual with special needs when the parent is no longer in a position provide care (Heller & Schindler, 2009). Interestingly, in keeping with the concept that such planning is frequently implicit in nature, research in this area also suggests that typically-abled offspring frequently are not included in the development of future plans or provided with explicit directives regarding their responsibilities related to their sibling with a disability (Heller, & Kramer, 2006; Heller & Kramer, 2009).

Though lacking in empirical evaluation, key person succession planning has been suggested to be an effective means of planning for the future (Bigby, 1996, 1997; Bigby et al. 2011). Specifically, through anecdotal caregiver reports, Bigby

(1996) found that even with the less formalized plans associated with implicit key person succession plans, parental caregiver expectations were generally fulfilled. Moreover, crisis transitions from parental care were largely averted, and urgent requests for services rarely occurred (Bigby, 1996, 1997; Bigby et al., 2011).

Based on their research**,** Bigby and colleagues have identified several important advantages to key person succession plans, including: 1) by mandating the intervention of a key person who is less emotionally involved than parents, parents are relieved from having to confront the challenges of making detailed transition arrangements; 2) nominated key people, with their open brief, can be responsive to the unexpected changes that occur after transition; 3) such an approach provides the security of an advocate to negotiate service provision, and ensures that the interests of the adult with an intellectual disabilities are foremost in decisions made about aspects of their life; 4) by handing decisions to key people with a different and perhaps less protective attitude, the conservatism of parental caregivers can be countered; 5) this approach allows for new opportunities to be created, and frees adults with intellectual disabilities from being tied into the particular visions of their parents and earlier times; and 6) such plans effectively ensure the continued availability of informal support in the lives of older people with intellectual disabilities (Bigby, 1996, 1997, 2004; Bigby et al., 2011).

Social network planning

In recognition of the importance of informal social support both for adults with special needs and for their aging caregivers, a social network approach towards future planning has also been suggested (Bigby, 1996, 2004; Etmanski, 2009; Hillman et al., 2012). Such an approach aims to seek out and involve members of the person's broader informal support network in the planning process and in supporting the individual with special needs during the post-parental care phase of their life (Whittaker, 1986). It should be noted that while this approach towards future planning is present throughout North America, the United Kingdom, and Australia, it is referred to under a variety of different names (i.e., "circles of support," "support circles," "support clusters," "microboards"). While there are slight differences in these various types of social network planning (i.e., inclusion of formal support people, size of the network, times of action/implementation), they all hold the major tenet of bringing together a group of people who all share the common vision of supporting the individual with special needs.

Within British Columbia, the social network approach towards planning is currently very present, and is currently promoted by the Crown Agency responsible for supports and services (Community Living British Columbia - CLBC) because such planning is seen as an effective strategy for strengthening safeguards and addressing issues of security (CLBC, 2011). For example, Planned Lifetime Advocacy Network (PLAN) in British Columbia has been offering training and advice to family caregivers relating to building personal support networks for the past two decades (PLAN, 2011). In fact, PLAN's work in this area is considered by many to have been one of the major developers and champions of this approach. As a result, organizations across the world have looked to PLAN's approach when developing and implementing their own approaches to future planning. For example, Pave the Way, an Australian organization devoted to helping families safeguard their relatives with a disability when the family is no longer able to provide care, developed their "Support Circles" program based off of much of PLAN's work (Pave the Way, 2006).

Based on the belief that relationships are the best guarantee of a safe and secure future, PLAN advocates for the creation of a personal support network around each person. Specifically, this network is a group of people who contribute in the present to the quality of life of the person with a disability (aka., the " focus person"), in preparation for their roles in the future when the focus person's primary caregiver is no longer able to provide care. Generally, network members carry out functions that are hard for the focus person to manage alone; this may mean practical help with housing, employment, and recreation, or simply developing closer ties to neighbours and the larger community. Beyond counseling family caregivers on how to create personal support networks, PLAN also is actively engaged in maintaining and managing the network after the family is no longer able to provide care, thereby helping to ensure that the network is maintained throughout the life of the focus person (Etmanski, 2000).

Another important form of social network planning that is present within a Canadian context is "microboards." A microboard is a fairly concrete form of social network planning, which brings together a group of family members and friends (between 5-8 individuals) to form a nonprofit society to address the support needs of the individual with a disability. These family members and friends are expected to perform specific roles within the microboard (ie president, vice president, secretary, treasurer) (Vela Canada, n.d.). By forming a nonprofit society, these support networks are eligible for agency-level funding; thereby, giving network members much greater control over how funds are allocated to meet the specific needs and preferences of the target individual (Vela Canada, 2012). While microboard members play a key role in managing the financial needs of the individual with an intellectual disability, members are also expected to play an active part in other aspects of the individual's life, including: facilitating community inclusion, acting as an advocate, monitoring services, and engaging in meaningful social and recreational activities (Vela Canada, n.d.).

The social network approach to future planning can serve several important functions. In particular, a network approach: 1) helps to combat the potential isolation faced by many older adults with intellectual disabilities, who generally do not have the social ties typical of individuals in their age range (i.e., a spouse, children); 2) it helps to keep key players in the focus person's life well-informed, up to date, and on the same page; 3) by expanding the planning process to include multiple others, planning often becomes more creative and varied, and the chances of the care-recipient's more intangible needs (e.g., friendships, recreational desires, etc.) being met increases; 4) such an approach ensures that there are ready advocates for the focus person during times of need, and that there are several people in the focus person's life dedicated to making certain that the individual is receiving the formal supports and services they need; and 5) importantly, involving multiple others in planning and post-parental care provides a forum for network members to support one another in supporting the focus person (Bigby, 1997; Bourke, 2009; Ontario Adult Autism Research and Support Network, 2008).

Despite the growing popularity of adopting a social network approach to future planning, it is largely lacking in empirical evaluation. Similar to the state of the research relating to key person succession plans, the minimal research that has been done relies largely on the anecdotal reports of caregivers. Overall, the reports of these caregivers suggest a high degree of satisfaction with this form of planning (Etmanski, 1997).

Finally, in discussing the social network approach, it is important to note that this form of planning does not necessarily have to be done at the exclusion of other future planning approaches. In particular, within the literature, there appears to be a large overlap between key person succession plans and a social network approach to planning (i.e., Bigby 1996; Bigby et al., 2011). For example, Bigby et al. (2011) suggest that these two approaches go hand-in-hand, in that both approaches conceptualize planning as a continuous process, and recognize the importance of building into plans mechanisms that are capable of responding to changed circumstances. In this way, Bigby et al. view nominated key people as potentially fitting into a broader social network approach to planning, with key people perhaps acting as leaders or facilitators to the larger support network.

Regarding more concrete forms of planning, similar to the relationship between key person succession plans and concretized planning, having social network plans in addition to concrete plans can be an asset in that network members can work together to bring specified plans to fruition. At the same time, social network members can act as safeguards against previously specified plans that are no longer suitable for the focus person and/or that no longer fit within the current service system.

Factors related to selecting particular future planning approaches

As noted in Part II, almost all of the research that has focused on identifying factors associated with future planning has defined future planning as the development of formal residential plans; the same is true for research aimed at identifying barriers to future planning. While this research has produced somewhat inconsistent results (Joffres, 2002), it at least provides some indication of factors that may be associated with selecting a concretized, detail-oriented approach to future planning (i.e., limited social support network; high engagement with formal services; the care-recipient having mild to moderate intellectual disability; single-mother family; high SES; parental aging). Unfortunately, even less is currently known about factors that may be associated with selecting more flexible and informal future planning approaches (i.e., key person succession plans, social network planning).

Bigby (1996) was, in fact, the only identified study that differentiated factors associated with concrete future planning from factors associated with informal future planning approaches -- specifically, key person succession plans. Similar to previous research findings (i.e., Heller & Factor, 1991; Smith et al., 1995), Bigby found that caregivers who were more involved with formal services were more likely than other caregivers to have made concrete plans. More interestingly though, Bigby also found that in instances in which the parental caregiver had a high degree of informal support in caring for the individual with a disability (e.g., another family member living nearby who was involved in helping with the care-recipient; a typically-abled offspring who had a strong relationship with the care-recipient), the caregiver was more likely to rely on informal plans. In instances in which the parental caregiver had limited support from others, the parent was more likely to have created formal plans, or not to have not planned at all. While Bigby provides some early indications as to the factors that might differentiate between selecting one approach over another, our understanding of these issues needs to be expanded significantly.

At this juncture, it is important to note that while research suggests that the minority of parental caregivers have made concrete plans, research also indicates that the majority of these caregivers have some form of informal or implicit future plans (Bigby, 1996, Bigby 2000). With this in mind, it seems possible that identified barriers to, or factors negatively associated with, concrete future planning may, in addition, be factors that are positively associated with selecting informal future planning approaches. For example, a high degree of contact with family and friends has been found to be negatively associated with making concrete plans (Essex et al., 1997). Importantly, as discussed above, Bigby's (1996) findings indicate that high contact with close family members is, in fact, associated with the creation of informal future planning, as caregivers may assume that these "high contact" social ties will play an integral role in the future care of the individual with special needs. This illustrates how a factor that is negatively associated with concrete planning, may also be a factor that is positively associated with other informal planning approaches.

The possibility that identified barriers to, or factors negatively associated with, formalized future planning may actually emerge as factors that are positively associated with more informal planning approaches makes sense intuitively, and, as illustrated above, there is some research to suggest this may actually be the case. At this juncture, research focused on uncovering the factors that are associated with more informal forms of future planning is clearly needed.

Purpose of Study & Research Questions

The above discussion provides an overview of three different approaches that parents might utilize when planning for the future of their adult children with intellectual disabilities. Despite growing recognition in the literature that there are different ways that parents can approach planning for the future, in reality, there continues to be limited understanding regarding the forms that parental future plans actually take in real-life practice, and regarding the reasons that parents plan in a given manner. As noted, a major reason for this dearth in the literature can be attributed to the fact that research focused on future planning has traditionally defined future planning as relating to the development of concrete plans. In an effort to both address this shortcoming in the literature, and to allow for the true breadth of parental future planning behavior to emerge, this study utilized Bigby's (1996) definition of future planning – i.e., "plans were defined as ideas or arrangements made by parents that concerned the care of their adult child with intellectual disability when parents had died, were incapacitated, or chose to cease being the primary carer" (p. 300). With this in mind, the primary objectives of this research study were as follows:

1) To gain a sense of the frequency with which parents actually implement the above discussed three future planning approaches (i.e., concretized, detail-oriented planning, key person succession planning, social network planning).

    1a) In exploring the frequency with which these planning approaches are utilized, gain an understanding of whether these future planning approaches are an effective means of categorizing or conceptualizing the ways that parents plan for the future.

    1b) If these three future planning approaches were not determined to be an effective method of categorization (i.e., if there is a great deal of overlap and/or variability in the way that parents plan), explore whether there is a more effective way of conceptualizing how parents plan for the futures of their children with intellectual disabilities.

2) To gain a more nuanced understanding of the factors (e.g., caregiver characteristics, care-recipient characteristics, family context characteristics) that may relate to parents planning in a given manner. This represents a sizeable addition to the extant research literature related to future planning which has, with the exception of Bigby (1996), largely been limited to exploring factors associated with no planning versus concrete planning (i.e., minimal attempts have been made to identify factors that may be associated with more informal types of planning). Moreover, the research efforts that have focused on identifying correlates of concrete planning have yielded inconsistent findings.

In an effort to meet these objectives, the researcher conducted a descriptive, exploratory study focused on parental caregivers' experiences with future planning. The guiding research questions of this inquiry were, "how do parents plan for the future of their adult children with intellectual disabilities?" and "why do parents develop future plans for their adult children with intellectual disabilities in a given manner?"

By gaining a more thorough understanding of how and why parents plan for the futures of their adult children with intellectual disabilities, it was hoped that several key aims would be met through this research, including:

1. Gaining information that will ultimately better support parents in planning for the futures of their children with intellectual disabilities.
2. Identifying salient factors that potentially distinguish between parents who select one form of planning over another in order to move toward tailoring planning supports and interventions to particular caregiving situations.
3. Identifying salient factors that appear to be associated with particular forms of future planning as a way of understanding how parents might be encouraged towards specific forms of future planning.
4. Gaining a greater understanding of the challenges that parental caregivers encounter when attempting to develop future plans so that adequate practical and professional knowledge and training may be organized.
5. Raising awareness regarding adults with intellectual disabilities and their aging families in Canada.

6. Identifying important areas of interest for future research related to future planning and adults with intellectual disabilities.

CHAPTER 3: METHODS

The primary purpose of this study was to gain a better understanding of the different forms that parental future planning can take in real-life practice, and to develop a preliminary understanding of the factors that are associated with parental caregiver's planning in a given manner. To do this, this study elected to use a more inclusive definition of future planning (i.e., ideas or arrangements made by parents that concerned the care of their adult child with intellectual disability during the post-parental care phase of their life) than has traditionally been used in research focused on future planning. This study builds on existing knowledge of future planning models in order to expand on our understanding of the applicability or suitability of different future planning approaches or interventions for a broad range of family situations. Ultimately, research in this area has the potential to provide knowledge that can assist service providers in more effectively tailoring future planning supports to parental caregivers.

Given the still developing nature of this area of research, I elected to utilize a qualitative research approach that was well-suited to the aim of developing a richer, more thorough understanding of parents' lived experiences with future planning for their adult children with intellectual disabilities, both from the perspective of how parents planned, and why parents planned in a particular way.

Qualitative Research Strategy: Interpretive Description

Interpretive description (Thorne, Reimer Kirkham, & MacDonald-Emes, 1997; Thorne, 2008), which is informed by the interpretivist framework (Oliver, 2011; Thorne, Reimer Kirkham, & O'Flynn-Magee, 2004), was used to address the research questions and objectives of this project. Interpretive description was initially developed as a nursing methodology (Sandelowski, 2000; Thorne et al., 1997). More recently, however, it has been presented as a methodology for all the applied disciplines (Thorne, 2008). This approach was developed in response to traditional qualitative methodologies (i.e., ethnography, grounded theory, phenomenology) that often fail to provide the timely knowledge needed by the applied disciplines to address real practice problems (e.g., supporting parental caregivers in developing future plans) (Thorne et al., 1997). Thorne (2008) defines interpretive description as,

> "…a qualitative approach that requires an integrity of purpose deriving from two sources: (1) an actual practice goal, and (2) an understanding of what we do and don't know on the basis of the available empirical evidence (from all sources). It constitutes a method that generates questions from that grounding, pushes one into the 'field' in a logical, systematic, and defensible manner, and creates the context in which engagement with the data extends the interpretive mind beyond the self-evident…to see what else might be there" (p. 35).

Given the applied nature of the present inquiry, and the ability for the information obtained from this investigation to have real-world practice implications, this methodology seemed particularly well suited to the research questions guiding this project. As I have tried to illustrate through the literature review on future planning (see Chapter 2: Literature Review), there is still much to be learned about the process of future planning. With this in mind, the focus of this inquiry was guided in large part by gaining an appreciation for the "holes" that still remain with respect to our understanding of how and why parents engage in future planning.

Interpretive description is not a prescriptive, circumscribed sequence of steps (Thorne, 2008). At its core, interpretive description involves knowing individual cases thoroughly and abstracting common themes and meanings from these cases. This knowledge of common patterns of experience can then be used to inform the principles that guide response to individual cases in the real world (Crabtree & Miller, 1999; Thorne, 2008; Thorne et al., 2004). Related to the current project, by conducting in-depth, semi-structured interviews focused on how and why parents future plan in a given manner with parents who actually have real-life experience related to this phenomenon, I sought to obtain a detailed understanding of individual parent's experiences with future planning. With this data, I attempted to identify common themes with respect to how and why parents plan for the futures of their children in a given manner (see Chapter 4: Results for a full reporting of the findings). I then explained how the knowledge obtained from this research might be used to modify future planning supports to better meet the needs of parental caregivers in practice settings (see Chapter 5: Discussion).

In keeping with interpretive description methodology, this investigation was located within a framework of existing knowledge based on the literature review. This framework provided a "foundational forestructure" (Thorne et al., 1998, p. 173), or orientation point, that informed design decisions and early data analysis. It was expected that this analytic framework would be challenged during the analysis process (Thorne et al., 1997); thereby helping to extend the boundaries relating to what is known about how and why parents of adults with intellectual disabilities future plan.

Ethics Approval

An ethics application for this project was submitted to the University of Victoria's Human Research Ethics Board on July 11, 2012, and approval was received on August 7, 2012. Data collection took place between August 2012 and May 2013.

Sample and Recruitment of Participants

Inclusion Criteria & Target Sample

The sampling strategy appropriate for this interpretive description study was purposive sampling (Thorne et al., 2004). The "lived experience" of parents of adult children with intellectual disabilities as it relates to the future planning process was of prime importance to this inquiry. With this in mind, the specific inclusion criterion for this study was being a parent of an adult who is 19 years of age or older who has an intellectual disability (i.e., significant limitations both in intellectual functioning and in adaptive behaviours, which extends to a variety of social and practical skills). The age of 19 years was selected, as, from a provincial services perspective, individuals 19 years and older are classified as adults, while individuals under 19 years are considered to be children and youth (British Columbia Ministry of Health, 2007).

I elected not to set a specific inclusion criterion regarding parents having engaged in future planning prior to taking in this research for a number of reasons. Specifically, in light of this study's purpose of capturing a broad range of future planning approaches, I did not want to inadvertently limit the study's focus by specifying particular types of future planning that potential participants were expected to have engaged in. Instead, I sought to uncover what parents, themselves, felt constituted “future planning.” In addition, given that a primary focus of this project was to gain a greater understanding of how and why parents future plan in real-life practice, I was open to the possibility of learning more about the reasons and/or factors that may relate to parents not engaging in future planning. It is worth noting, however, that while no inclusion criterion was set regarding participants having engaged in future planning, recruitment materials clearly specified that future planning was the focus of this research. With this in mind, it is possible that parents who did not consider themselves as having engaged in future planning self-selected out of this research.

For the purpose of garnering a range of experiences related to future planning, I initially sought variation within the sample in terms of the type(s) of future planning (i.e., concretized, detail-oriented planning; key person succession planning; social network planning) that parents indicated they had utilized on the Future Planning Approaches Questionnaire (Appendix A; see Forms of Data Collection for more detail). However, after the first few interviews, it became apparent that the future planning approach(es) that participants indicated they had utilized on the questionnaire did not necessarily coincide with how they described their future plans during their subsequent phone interviews. For example, a participant might indicate that they were only utilizing a concretized, detail-oriented approach to planning, but in interviewing him or her, it would become apparent that their future plan also drew on elements of both key person succession planning and social network planning. As will be discussed in more detail below (see Chapter 4: Results for more information), it became apparent early on in the data collection process that the majority of parents appeared to be using an amalgam of approaches when future planning, frequently very uniquely tailored to their own family contexts, needs, and values. With this in mind, early in the data collection process, it began to seem both impractical and inconsistent with what was emerging from the data to be explicitly seeking out specific forms of variation related to future planning when conducting the semi-structured phone interviews.

When I began recruiting participants for this project, I also initially sought variation – again, through the use of the Future Planning Approaches Questionnaire (Appendix A) -- in the age and gender of participants, age and gender of the adult child with an intellectual disability, SES, ethnicity, and family structure (i.e., single caregiver vs. shared caregiving). Unfortunately, recruitment proved to be much more challenging than initially anticipated. As a result, there was not a surplus pool of potential participants within which I could pick and choose in order to maximize the variation in the sample in the domains noted above. It was felt that hearing from a relatively large number of participants(n=28), was desirable to having a much smaller, more diverse sample of participants. Despite difficulties in recruitment, the sample was still fairly diverse with respect to the ages of both the parent and the individual with intellectual disability, SES, gender of the individual with an intellectual disability, and, to some extent, gender of the parent and family structure. A complete description of the sample is included in Chapter 4: Results, and a more a thorough discussion of the implications of these recruitment difficulties is contained within Chapter 5: Discussion.

Participant Recruitment

A strategy commonly used to recruit parental caregivers for participation in research is to enlist the assistance of agencies providing services to people with intellectual disabilities and their families (Bigby & Balandin, 2004; Jokinen, 2008). With this in mind, I approached provincial agencies that provide services to adults with intellectual disabilities (e.g., CLBC, British Columbia Coalition of People with Disabilities, The Cerebral Palsy Association of British Columbia, etc.) and secured their support in circulating information about this research project materials to caregivers on their email lists.

To date, research has largely been limited to caregivers who are already in receipt of formal services and/or who are already known to service agencies (Haley & Perkins, 2004; Heller & Factor, 2008; Jokinen, 2008). It is possible, however, that "hidden" caregivers (i.e., caregivers unknown to the formal service system) may have unique perspectives to offer with respect to their engagement in the future planning process (Haley & Perkins, 2004). With this in mind, I also attempted to recruit participants from alternate, non-disability-specific sites; thereby, increasing the likelihood of recruiting caregivers who may have been unknown to the formal service system. For example, I contacted community services for older adults in the general population and various other community groups (e.g., churches, senior recreation centers) and requested their support in disseminating information about this research project to their users.

Finally, I also attempted to recruit participants through the use of the snowballing technique, in which I encouraged people who had already participated in this research to pass information about this study along to other parents they knew who had adult children with intellectual disabilities. As several participants indicated that they were part of informal parent support groups and/or were generally well-connected with other parents in the disabilities community, this appeared to be a useful strategy.

In total, 28 parental caregivers were recruited to complete semi-structured phone interviews, which met the pre-established goal of interviewing 24-30 parents about their future planning experiences. It was felt that this relatively large number of interviews yielded an adequate breadth of perspectives related to the topic of future planning.

Forms of Data Collection

Qualitative Data

I attempted to collect qualitative data through the Future Planning Approaches Questionnaire, which was developed for this project (see Appendix A). On this questionnaire, participants were asked to indicate the type(s) of future planning they believed they had engaged in, and to provide brief written responses to three open-ended questions aimed at gaining a greater sense of what their respective future plans looked like, and what they perceived to be the pros and cons of the approach(es) they had selected.

On the Future Planning Approaches Questionnaire, participants were also asked to indicate whether they would be open to taking part in a follow-up phone interview. With the exception of one individual, all people who completed the Future Planning Approaches Questionnaire indicated that they would be open to follow-up phone contact; and of all the participants who indicated being open to follow-up phone contact, all but one individual elected to take part in a follow-up interview when they were re-contacted about this possibility (n=28). Perhaps because the vast majority of individuals who completed the questionnaire believed they would be engaging in a follow up phone interview, the open-ended questions on the questionnaire were frequently left blank and/or completed with very minimal detail. In support of this hypothesis, on the questionnaire, several participants even explicitly noted that they would prefer to take part in an interview as opposed to trying describe their future plans in writing on the questionnaire. As a result of this, the Future Planning Approaches Questionnaire did not yield the rich qualitative data that it was expected to produce.

The primary qualitative component in this interpretive description study was one-on-one phone interviews with all of the parents who completed the Future Planning Approaches Questionnaire and who were open to a follow-up phone interview (n=28). As noted by Thorne (2008), semi-structured interviews are very well suited to interpretive description methodology, as they allow the researcher to gain a very detailed understanding of the participant's experience with the phenomenon (i.e., future planning) in question.

While the interview questions (see Appendix B) were formulated in advance, these questions were flexible and, as such, were modified and tailored to accommodate the themes and ideas that emerged in specific interviews (Bryman, Teevan, & Bell, 2009). Interview questions were designed to be short, easy to understand, and open-ended in order to encourage discussion, while still accounting for a wide-range of levels of education and understanding. These questions simply served as a guide for the interviewer. While modifying interview questions to accommodate the unique needs and experiences that arose in specific interviews, I always sought to maintain the overarching objectives of using these semi-structured interviews as a means of gaining a richer understanding of *how* parents plan for their adult with children with intellectual disabilities, and *why* parents plan in a particular way.

Quantitative Data

Within this research, limited quantitative data was collected in the form of basic demographic information (e.g., age of parent/individual with intellectual disability, income). This information was collected on the Future Planning Approaches Questionnaire and at the beginning of each follow-up phone interview.

Data Collection Procedures

As discussed above (see Sample and Recruitment of Participants), various agencies and community services were approached for the purpose of exploring their willingness to disseminate information about this study (see Appendix C). If the approached agencies/community services agreed to support this research study, I emailed them a research letter for potential participants (see Appendix D), along with the consent form (see Appendix E). I asked these supporting agencies and community services to email these two documents to their various email lists and to anyone else who they believed might be suitable for participation and/or in contact with people who might be suitable for participation.

The research letter for potential participants detailed the focus of the study, clearly outlined what participation involved (i.e., required tasks, time commitment), and explained how a person can take part in the research. Specifically, the letter instructed interested participants to open the attached consent form, to read it, and then to type their name and date in the space given at the bottom of the form. They were then asked to email the completed consent form to the researcher at the given email address. Upon email receipt of the completed consent form, I emailed the participant the Future Planning Approaches Questionnaire (see Appendix A), along with a document describing the three future planning approaches (see Appendix F). Within the body of this email, the participants were provided instructions regarding the completion of the questionnaire and how to return the completed questionnaire to the researcher (see Appendix G). Upon receiving the completed questionnaire, I sent the participant a brief email confirming receipt of the questionnaire, and thanking them again for their participation in this research project (Appendix H).

At the end of the questionnaire, participants were asked if they were willing to be contacted by the researcher at a later date for a follow-up phone interview to discuss their experiences with future planning in more depth. It was emphasized that participants were under no obligation to agree to follow-up contact, and that indicating being open to follow-up contact did not guarantee that they would necessarily be contacted.

As mentioned above, in-depth phone interviews were conducted with participants who completed the Future Planning Approaches Questionnaire and who were willing to engage in follow-up phone contact. Participants who indicated being open to a follow-up interview on the Future Planning Approaches Questionnaire were contacted by phone or email to determine if they were, in fact, still willing to engage in a phone interview and to describe the focus of the interview and the time commitment involved (approximately 60-90 minutes). At that time, I again emphasized that they were under no obligation to participate. If the participant agreed to participate in a follow-up interview, an interview was scheduled with them to take place in the near future. As stated, of the 29 individuals who indicated being open to follow-up phone contact on the Future Planning Approaches Questionnaire, all but one individual ultimately elected to take part in a follow-up interview (n=28).

At the beginning of each interview, I re-reviewed consent procedures with the participant (Appendix I), provided a brief overview of the objectives of the interview, and answered any questions the participant had. Following this introduction, I began with the interview questions, moving from the more general to the more specific (i.e., flow from introductory questions and statements, to transition question, to key questions, to ending questions and statements). As stated previously, these questions simply served as a guide. While interview questions were adjusted and adapted based upon the individual interviews, I always sought to maintain the basic focus of the discussion of gaining a deeper understanding of how and why parents future plan for their adult children with intellectual disabilities in a particular manner.

At the end of each interview, I summarized the main themes that arose during the interview, and I asked participants for their feedback on these reflections. This served as an opportunity for participants to clarify points that I may have misinterpreted, and to raise any last minute points that were not addressed during the discussion but that they felt were also relevant to the inquiry (Thorne, 2008).

Throughout the interviews, an audio-recording device was running. This helped to ensure that none of the ideas, opinions, or perspectives shared during the discussions were lost. The participants were fully informed about the presence of the audio-recording device and about the possible uses of the audio recordings. In addition, following each interview, I prepared summary notes, highlighting the major points and themes that emerged (Kreuger & Casey, 2000; Padula et al., 2003), and making note of any reflections on the process and/or the larger inquiry.

It should be noted that important aspects of this research project were computer based (e.g., recruiting participants via email, disseminating and collecting completed questionnaires via email). This procedure necessarily limited the sample to a computer-literate population; however, given that computer use has become increasingly common in recent years, particularly within the older adult population (Wagner, Hassanein, & Head, 2010), it was believed that this would not likely pose a major limitation to the study design. Moreover, the ease of data collection that this method afforded, in conjunction with the increased chance of sampling from a broader geographical area (i.e., throughout British Columbia, as opposed to being limited to the Greater Victoria Region), were felt to offset the possible limitations posed by being restricted to a computer-literate population.

Data Analysis

Qualitative Data Analysis

The digital recordings from the interviews were transcribed verbatim. Following transcription, I initially sought to sort the transcripts according to caregivers who selected a particular future planning approach or combination of approaches (i.e., concretized, detail-oriented planning, key person succession planning, social network planning); however, this step was ultimately unfeasible as there appeared to be so much overlap in the approaches that were being utilized (see Chapter 4: Results). Given that categorizing the interviews according to predetermined future planning approaches did not appear to fit with the data, I attempted to allow meaningful distinctions and categories within the data to emerge over time through a process of repeated immersion in the data and reflection. This approach to the initial data analysis was very much in keeping with interpretive description.

Specifically, an interpretive description approach advocates for the use of inductive analytic techniques (Thorne et al., 2004). Thorne and colleagues (2004) strongly warn against overinvestment in the early detailed coding that is typical of some qualitative traditions (i.e., grounded theory) (Corbin & Strauss, 2008), warning that premature allegiance to ill-fitting categories can constrain the creative iterative process of "comprehending, synthesizing, theorizing, and recontextualizing" that interpretive description requires (Morse, 1994, p. 30). Instead, Thorne et al. (1997, 2004) advocate for analytic techniques that encourage repeated immersion in the data prior to beginning coding, classifying, or creating linkages (Lincoln & Guba, 1985). They suggest that it is crucial to move in and out of the detail in the data in an iterative manner, repeatedly asking, "what is happening here?" and, "what am I learning about this?" as a way of orienting oneself in the data, and remaining cognizant of the data's contextual nature.

With this in mind, during the "immersion and reflection" phase, I read through each transcript in its entirety prior to beginning coding, and recorded any initial impressions that arose (Thorne, 2008). These initial impressions were then used as an orientation point as I progressed to the step of scrutinizing individual transcripts for repeating ideas and topics of importance; which, were then grouped and categorized for developing themes (Auerbach & Silverstein, 2003). These emergent themes and topics of importance from individual transcripts were then examined and compared across transcripts. Through this process, meaningful distinctions began to emerge in the data, and, in turn, potentially useful ways of conceptualizing or constructing the data became apparent.

By examining the points at which the resulting perspectives of participants differed and converged, I sought to construct a cumulative picture representing the researcher's best approximation of what is "really" going on (Thorne, 2008), while also recognizing that it was impossible to account for all sources of variation. In this way, I attempted to move beyond surface description to develop a coherent conceptual description that extended beyond individual instances of things and transcended the perceptual world (Oliver, 2011).

As noted previously, the Future Planning Approaches Questionnaire did not yield the rich qualitative data that it was expected to produce. Many participants left the questions blank, or provided very minimal detail. As a result of the very limited information obtained through this questionnaire, I elected not to formally analyze questionnaire responses. Instead, in the instances in which a participant provided qualitative information on the questionnaire, I drew on this information during the follow-up interview -- reminding the participant of what they had indicated on the questionnaire and asking them to expand, and/or asking specific follow-up questions related to their responses on the questionnaire. In this way, while not formally analyzed, the qualitative questionnaire responses were incorporated into the follow-up phone interviews, which were always envisioned to be the primary qualitative component of this project.

To aid in organizing and making sense of the large amount of qualitative data that this project yielded, I utilized Dedoose, which is a qualitative data analysis program developed by SocioCultural Research Consultants.

Quantitative Data Analysis

Quantitative data, which was in the form of basic demographic information, was analyzed through the calculation of means, ranges, and frequencies.

Rigour in Qualitative Research

A number of scholars have proposed criteria for evaluating the validity of qualitative inquiries (i.e., Lincoln & Guba, 1985; Marshall, 1990; Maxwell, 1990; Sandelowski, 1986, 1993; Smith, 1990; Thorne, 1997, etc.). Despite the proliferation of proposed validity criteria, Lincoln and Guba's (1985) criteria for enhancing the trustworthiness of qualitative work continue to be viewed as the "gold standard" in qualitative research (Whittemore, Chase, & Mandel, 2001, pg. 527). Specifically, Lincoln and Guba identify four key aspects of trustworthiness that are relevant to all research studies – whether quantitative or qualitative – including: 1) truth value, 2) applicability, 3) consistency, and 4) neutrality. Based on the philosophical and conceptual differences between qualitative and quantitative approaches, Lincoln and Guba argue that these four criteria must be defined differently for qualitative and quantitative research.

Within the realm of qualitative inquiries, Lincoln and Guba (1985) view the criterion of truth value – which is considered to be the most important criterion for the assessment of qualitative research (Krefting, 1990) -- as being concerned with checking the *credibility*, or truthfulness, of findings. In order to establish credibility, I utilized a number of recommended techniques (i.e., Krefting, 1998; Lincoln & Guba, 1985; Sandelowski, 1986), including prolonged engagement with participants (i.e., 28 semi-structured interviews were conducted, each with an average duration of 58.33 minutes); triangulation of methods (i.e., collection of quantitative and qualitative survey data, in addition to qualitative interview data); triangulation of data sources (i.e., comparing research participants with different view points and experiences relating to the future planning process; comparing collected data to other published studies on future planning for adults with intellectual disabilities); peer examination (i.e., consulting with supervisor and doctoral committee members throughout data collection and data analysis to discuss insights, problems, and emerging hypotheses as they arose; having each doctoral committee member review two or three interview transcripts as a way of checking initial impressions and interpretations); and member-checking (i.e., during semi-structured interviews, initial impressions and interpretations were shared with participants on an on-going and informal basis).

Lincoln and Guba (1985) define the criterion of applicability as relating to the *transferability*, or fittingness, of findings in a qualitative study from one context to another. As noted by Lincoln and Guba, the primary method for enhancing transferability is through the use of thick description (Ryle, 1949; Geertz, 1973); which, is when a phenomenon is described in sufficient detail so that it begins to be possible to evaluate the extent to which research findings can be transferred to other times, settings, situations, and people. Within this study, thick description was utilized in that the large number of time-intensive, semi-structured interviews that were conducted yielded over 500 pages of interviews transcripts detailing participants' experiences with the future planning process**.** This large amount of data made it possible to draw connections and identify patterns in the data across a range of participants, and to place findings in the broader context of the existing literature on future planning.

Further enhancing transferability, in the following chapter (Chapter 4: Results), the participants and their family contexts have been described thoroughly, so that readers might know that the results relating to future planning are only true for individuals in similar circumstances. Readers should not generalize the results of this study to all parents who engage in future planning for their adults sons and daughters with intellectual disabilities; however, the overall themes and patterns may be relevant in varying ways to many parents in this situation.

Lincoln and Guba (1985) conceptualize the criterion of consistency as *dependability* (i.e., findings are consistent and could be repeated) within a qualitative research context. In an effort to increase the dependability of this research project, I provided dense description regarding the exact methods of data collection, analysis, and interpretation employed in this research. Such dense description of methods provides the reader with important information regarding how repeatable this study might be, and under what conditions. Dependability was also enhanced in this study through the use of a field notebook, in which conversations with committee members and decisions about the research process were tracked, so that others might be able to track the timing of these processes in relation to the timing of decisions related to methodological changes, code development, and theme development. Finally, consulting with doctoral committee members (i.e. peer examination), as well as other experts in the area of intellectual disabilities, regarding the development of the research plan and its subsequent implementation was also another important means through which the dependability of this research was maximized.

Finally, Lincoln and Guba (1985) argue that within qualitative research, the criterion of neutrality takes on the meaning of *confirmability*; which is defined as the extent to which research findings are shaped by participants and not by the researcher's bias, motivation, or interest. A primary strategy that I employed to enhance the confirmability of research findings was to engage in a process of reflexive analysis. Specifically, throughout the research process, I used personal response documentation, or journaling, as a means of recording my self-awareness during and after interactions with participants, and periodically throughout the data analysis process. This exercise enabled me to reflect on the ways in which my own values, interests, and experiences might impact upon this research. This heightened awareness increased my ability to “check” my biases; however, in recognition of the fact that it is not possible – nor desirable - for the researcher’s influence to be entirely removed from the research process, I also elected to explicitly outline personal and professional biases and experiences that had the potential to shape this inquiry (see Chapter 1: Introduction, Researcher’s Biases).

CHAPTER 4: RESULTS

Introduction to the Participants

The demographic information related to the 28 parental caregivers of adults with intellectual disabilities who completed a questionnaire and took part in an in-depth follow-up interview is presented below.

Table 1: Participant Demographics (n = 28)

Variable	Average Value	Range / Frequency
Parent's Age	57.357 years	46-77 years 40-49 years: 3 50-59 years: 13 60-69 years: 11 70+ years: 1
Child's Age	26.143 years	19-43 years 19-24 years: 14 25-29 years: 7 30-34 years: 2 35+ years: 5
Parent's Gender		Males: 5; Females: 23
Child's Gender		Males: 11; Females: 17
Household Income	$81,423.00	$22,000-$200,000
Marital Status		Married: 18 Single: 10
Level of Impairment*	2.96	1-5
Years of Education	15.536 years	12-20 years
Living Situation of Child		Parent's Home: 19 Own Home: 5 Home Share: 1 Group Home: 3

**Level of impairment as assessed on a 5-point scale, with 1 being "Very Low Impairment" (i.e., requiring minimal assistance with day-to-day tasks) and 5 being "Very High Impairment" (i.e., requiring assistance with all aspects of daily life).*

Key Findings

Overview

The keys findings derived from analysis of the interview data from 28 parental caregivers of adults with intellectual disabilities are presented below. First, the proportion of the sample that showed evidence of each of three future planning approaches (i.e., Concretized, detailed-oriented planning, key person succession planning, social network planning) is presented, and the observed variability in the way these approaches were implemented is discussed. Second, through the data analysis, two groups emerged with respect to how parents plan for the future of their adult children with intellectual disabilities – namely, Concrete Planners and Informal Planners. Factors that appear to distinguish between Concrete Planners and Informal Planners were identified. These factors are presented below, and the way in which they appear to support concrete planning and informal planning is illustrated through relevant participant quotes. Finally, third, key themes related to improving the future planning process - regarding both the formal service system's relationship with future planning, and the ways in which parents, themselves, approach future planning – were identified across groups. These themes are presented, again drawing on participant quotes to illustrate key points.

All quotes contain an identification code. Each participant was identified as being either a Concrete Planner (i.e., "CP") or an Informal Planner (i.e., "IP") and assigned a number within the respective planning group (i.e., "CP1", IP1", etc.). All names have been changed to protect participants' privacy.

1. Evidence of Three Future Planning Approaches

Of the 28 parental caregivers interviewed, 26 (92.86%) parents showed elements of concretized, detail-oriented planning, 22 (78.57%) parents showed elements of key person succession planning, and 18 (64.29%) parents showed elements of social network planning (see Literature Review for a description of these three future planning approaches). 14 (50.00%) parents showed elements of all three future planning approaches when discussing their plans for the future of their children with intellectual disabilities; 10 (35.71%) parents showed elements of two future planning approaches in their respective future plans. Overall, 85.71% of the sample showed evidence of utilizing two or more future planning approaches when developing future plans.

As discussed above (see Literature Review), concretized, detail-oriented planning is generally viewed as relating to three key areas of the care-recipient's life – namely, formalized financial plans, formalized residential plans, and formalized arrangements with respect to guardianship and/or other less restrictive alternatives. With respect to financial planning, almost all parents (26/28) had developed some degree of concretized financial plans (i.e., setting up a Registered Disability Savings Plan (RDSP), establishing a discretionary trust fund and appointing a trustee or group of trustees). The extent of this financial planning, however, varied widely. For example, several parents had only taken the step of setting up an RDSP. In contrast, other parents had set up an RDSP, and had established a discretionary trust fund and appointed a trustee or a group of trustees to manage the trust. In addition, several parents, as illustrated by the quote below, had also dedicated significant time to developing a will that clearly articulated how personal assets should be divided and allocated, and developed plans to help ensure that any inherited assets would not negatively impact their child's eligibility for Persons with Disabilities Assistance.

> We have the wills set up. We've made sure it designates in our will what is required to ensure [my son's] financial security…so his provincial disability benefits aren't affected…Like if I'm gone and my two children inherit from my estate, it's divided equally and then [my son's] share goes into a discretionary trust fund so that he is protected from his monthly government income – his disability income - being affected. So we have that in place. (CP7)

A smaller subset of parents (15/28) showed concretized future planning with respect to their child's future place of residence. Of these 15 parents, five parents had already purchased homes for their children and had made arrangements for their children to be supported within their homes, five parents had taken steps towards purchasing a home for their child (i.e., securing funding from CLBC for in-home support for their child, contacting a lawyer to explore their child's ability to own property, looking at potential properties), three parents had placed their children in group home facilities, one parent had placed their child in a home share living environment, and one parent had placed their child's name on a waitlist for a group home placement.

Many parents (19/28) showed elements of concretized future planning in the domain of guardianship and/or other less restrictive alternatives (i.e., obtaining committeeship and then designating an alternate committee; establishing a representation agreement and designating someone to act as an alternate representative and/or designating a monitor for the representation agreement).

The degree to which an "alternate's" roles were made explicit, however, varied widely across parents.

Given that concretized, detail-oriented planning is viewed as being related to three key areas (i.e., finances, place of residence, guardianship/decision-making responsibilities), it is important to note that there was a great deal of variability in the *degree* to which this approach was implemented within the subset of parents viewed as utilizing a concretized planning approach. For example, some parents within in this subset showed concretized planning that was limited to very circumscribed financial arrangements, whereas other parents within this subset exhibited concretized planning in all key areas.

A great deal of variability was observed in the way in which key person succession planning was utilized. As stated, 22 of the 28 parents in this study showed elements of key person succession planning. Some parents showed evidence of very concretized and explicit key person succession planning. For example, these parents used legal channels to officially designate someone, frequently a typically-abled child or another close family member, as a trustee/alternate representative/monitor/alternate committee for their child, and, as evidenced by the following quotation, also provided the designated key person/people with fairly explicit guidelines relating to their duties and responsibilities.

> I created a trust for [my daughter] and I have three trustees, and I seriously thought through who those three people should be in terms of knowing [my daughter] and being able to manage the trust. So we got together, those three people got together about a year and a half ago, and we had a pretty thorough discussion about what I felt [my daughter's] needs were, what I

> saw for her future, and how these people could help me fulfill that dream in the event I'm not around (CP8)

Other parents, in contrast, adopted a more informal approach to key person succession planning. For example, several parents went through the process of having someone legally designated as a trustee/alternate representative/ monitor/alternate committee for their child with an intellectual disability, but provided that key person with very little guidance or direction with respect to what their roles and responsibilities would be. By way of an example, one mother, when asked if she had made her expectations explicit relating to her typically-abled daughter's role as monitor on the representation agreement, responded:

> We've given [our typically-abled daughter] the representation agreement and she's the monitor on the representation agreement. So she has a copy of that. So, you know, it's in there that she would be the decision-making person when we're gone. But, no, we haven't written down for her more than that what her duties will be simply because we know…[our typically-abled daughter] steps up if anything comes up with [our daughter with a disability]…(CP13)

Still other parents approached key person succession planning even more informally. For example, a few parents, in the absence of establishing legal designations, forged informal arrangements with close others (i.e., typically-abled children, other close family members) to act as "key people" on their children's behalves. For example, one parent who had engaged in very minimal concrete planning, had an informal arrangement with her typically-abled daughters to act as "key people" for her son:

> …We talk about it, like the girls talk about it… I know [my son's] sister, my daughter, is a special ed assistant in the school system so she will definitely make sure he's looked after and he's getting what he needs care-wise...Getting programs and whatever else in place. And the other, like my step-daughter…probably would be more on the financial end of it, she would

> make sure of all that…That's what her job is, is looking after finances… so I think she'd have a handle on how much he needs or any of that. And they live right here in town so they would be more apt to be a big part of his life. (IP6)

Similar to key person succession planning, there was a great deal of variability in the way the parents in this study incorporated social network planning into their future plans. As stated, 18 of the 28 participants interviewed engaged in some form of social network planning when developing plans for the future of their child. Like key person succession planning, some parents approached social network planning in a very concretized fashion. For example, as a way of securing individualized funding from CLBC, some parents joined together with other family members and friends to create non-profit societies for the purpose of establishing microboards (see Literature review for discussion of microboards). Because of the funding that is attached to these boards, there are specific guidelines with respect to who can be on a microboard**,** and the different roles that must be filled by microboard members**.** As a result of these specifications, parents who formed microboards were engaged in very concrete social network planning, with social network members having clear roles and responsibilities with respect to the individual with an intellectual disability. One parent, in discussing the microboard she and her husband had formed for their daughter, provided a useful overview of the different roles maintained by microboard members:

> …My mom is my secretary. She's a very good secretary! So there's my mom, my friend…who does the books. She's a financial person as well, so I run things by her. My brother, [my husband] of course, and myself are on the board. [My daughter] has some friends…And I'm going to ask them if they would like to be on the microboard…They would be overseers…that's a really good thing, to have friends as overseers…[It's] more people keeping an eye on things. (IP3)

Concrete social network planning was also evident in a few parents who utilized certain organizations (i.e., Planned Lifetime Advocacy Networks (PLAN), Lifetime Networks) in order to gain assistance with developing a formal support network (i.e., "circle of support", "network of friends") around the individual with an intellectual disability. In these instances, parents formally asked individuals in their life and/or their child with an intellectual disability's life to be part of a support network. Support network members, under these circumstances, were often not prescribed specific tasks; however, they were generally viewed as being responsible for helping to engage the adult child socially/recreationally. For example, when asked why she chose to utilize PLAN's services, one mother stated,

> We, personally, are coming into PLAN with a network of friends and a community connector so we are presenting that to PLAN and just letting them continue on with them. Just so that there is somebody in charge of [my daughter's] social life to make sure that there are always people in her life**.** (CP6)

Other parents eschewed utilizing the services of an organization in setting up a formal network - often due to the associated costs of using these services - but still appeared to be engaging in a more formal type of social network planning by explicitly seeking commitments from family members and friends to play a role in the future of the individual with an intellectual disability. For example, one mother, in talking about the role others would play in her son's future, stated, "…we have had conversations and discussions, and we do have commitments from a number of people that I can feel sure if I die tomorrow will be in [my son's] life and ensure his life is good" (CP7).

Still other parents engaged in much more informal forms of social network planning. These parents generally viewed a larger network of people (i.e., a group of family members/friends/community members) as playing an important role in the post-parental care phase of their child's life, in spite of never having had explicit discussions to this effect with the respective network of people. For example, one parent, in reflecting on why she had always placed emphasis on facilitating and fostering strong relationships between her son with an intellectual disability and the broader community, stated,

> I guess I never even thought of why I have been building relationships like that…I kind of was going along at full speed, never even thinking about that they were going to be part of [my son's] future, and obviously that's why you choose people like that….It's like gathering up people that you know are going to have an active part in his life and have a different skill set….I know that if something should happen to me tomorrow then he would be well looked after by…any of my friends or social network. They would be more than happy to be taking over. (IP6)

Many parents who showed elements of more informal social network planning were confident that a group of people would naturally come together, without active intervention on their part, to support their child with an intellectual disability in the event of the parent's death or illness:

> I'm sure if I died tomorrow, six or eight people would be at the table and really putting their heads together around how to help [my daughter] and what best decisions should be made for her. (CP8)

> If push came to shove and we had to go out to the community, we know there would be people that would step up - just because they know [my daughter] or they've seen her. The most often thing said of caregivers when they take her out and come back is, "Oh, my God, she knows everybody. Everybody knows her." (CP11)

While the majority of parents interviewed in this study were found to be implementing more than one future planning approach (85.71%), some parents were also found to be implementing a given future planning approach in more than one way. For example, a few parents exhibited both concrete and more informal forms of social network planning. For instance, one parent had established a microboard – a very concrete example of social network planning – which she viewed as managing the practical concerns of her daughter's day-to-day future life; she had also developed a more informal social network around her daughter mainly comprised of her daughter's friends, which she viewed as playing an equally important, though different, supportive role in her daughter's future. Another parent in this study exhibited both formal and informal key person succession planning. This parent had gone through legal channels to have her typically-abled child designated as an alternate representative for her child with an intellectual disability; at the same time though, this parent also viewed one of her siblings as being the person most likely to step in and oversee her child with a disability's care if her typically-abled child was unable to manage things and/or if she died relatively soon (i.e., when her typically-abled child was still, perhaps, too young to take on the responsibility of managing their sibling's care). In both of these examples, it appears that the parents were utilizing a given future planning approach in more than one way in an attempt to bolster future plans, and thus, further safeguard their child with an intellectual disability.

It is also interesting to note that when developing future plans, many parents were found to have utilized more than one future planning approach when developing plans for a given aspect of their child's future life. For example, one parent, in developing plans related to decision-making responsibilities, utilized a combination of concrete key person succession planning (i.e., having one of her typically-abled sons designated as an alternate committee) and concrete social network planning (i.e., setting up a microboard, which she viewed as playing a supportive role in the event of her typically-abled son having to make difficult decisions related to the individual with an intellectual disability). Again, this layered approach to planning appeared to be a way in which parents sought to strengthen their plans, and, in turn, protect their child from future harm.

2. Conceptual Groupings: Concrete Planners and Informal Planners

Based on the above discussion, it is clear that utilizing a range of future planning approaches was the norm, rather than the exception, for the parents interviewed in this study. Moreover, as discussed, even within the subset of parents utilizing a given planning approach, there was a great deal of variability with respect to how the approach was implemented. In this way, a parent who was found to be using a social network approach to planning could have future plans that looked entirely different from another parent also found to be using a social network future planning approach; the same can also be said for parents using a concretized planning approach and/or a key person succession planning approach. With this in mind, "pure" groups of parents who engaged in each of the three future planning approaches did not emerge (i.e., parents who engaged in concretized planning vs. parents who engaged in key person succession planning vs. parents who engaged in social network planning). In effect, the overlap in the use of future planning approaches within this sample, in conjunction with the variability in the way in which the approaches were implemented, made it impossible to make meaningful comparisons between parents who engaged in one form of future planning over another.

While discrete groups of parents who engaged in one of three future planning approaches did not emerge in this study, what did emerge through the analysis process were two distinct groups of parental planners who varied in terms of the degree of formalization of their plans. In particular, the 28 parental caregivers who were interviewed were found to have future plans that were either predominantly concrete or predominantly informal. With that said, the parents in this study could be seen as belonging to one of two groups – namely, “Concrete Planners” or “ Informal Planners.” “Concrete Planners” were defined as parents who had developed plans in which the majority of key planning areas were formalized. For example, Concrete Planners generally had made concrete arrangements with respect to where and how their child with an intellectual disability would be living; concrete financial arrangements; and concrete arrangements with respect to decision-making responsibilities. “Informal Planners” were defined as parents who had developed plans in which the majority of key planning areas were largely informal. Parents within the “Informal Planners” group generally had informal or open-ended plans surrounding where and how their child would be living; open-ended financial arrangements; and/or open-ended planning surrounding decision-making responsibilities – a decision-maker may or may not have been legally designated, but roles and responsibilities were left fairly open or vague.

Table 2: Concrete Planners and Informal Planners

Variable	**Concrete Planners (n=15) Average/Range/Frequency**	**Informal Planners (n=13) Average/Range/Frequency**
Parent's Age	59.6 years/46-77 years 40-49 years: 2 50-59 years: 4 60-69 years: 8 70+ years: 1	54.769 years/48-61 years 40-49 years: 1 50-59 years: 9 60-69 years: 3 70+ years: 0
Child's Age	28.4 years/ 19-43 years 19-24 years: 6 25-29 years: 4 30-34 years: 1 35+ years: 4	23.538 years/19-36 19-24 years: 8 25-29 years: 3 30-34 years: 1 35+ years: 1
Household Income	$104,615.38/ $40,000-$200,000	$58,230.77/$22,000-$100,000
Level of Impairment*	3.467/2-5	2.385/1-5
Marital Status	Married: 12 Single: 3	Married: 6 Single: 7
Years of Education	16.133 years/12-20 years	14.846 years/12-18 years
Living Situation	Parent's Home: 6 Own Home: 5 Home Share: 1 Group Home: 3	Parent's Home: 13

**Level of impairment as assessed on a 5-point scales, with 1 being "Very Low Impairment" (i.e., requiring minimal assistance with day-to-day tasks) and 5 being "Very High Impairment" (i.e., requiring assistance with all aspects of daily life).*

Within the sample, 15 parents were identified as being "Concrete Planners;" 13 parents were identified as "Informal Planners." Table 2 provides relevant demographic details for the Concrete Planners and the Informal Planners in this study. As is evident from Table 2, Concrete Planners were, on average, 4.831 years older than Informal Planners, and their children with intellectual disabilities were, on average, 4.862 years older than the children of Informal Planners. Concrete Planners had a yearly household income that was, on average, $46,384.58 higher than the yearly income of Informal Planners, and they had received, on average, 1.287 years more education than Informal Planners. Finally, the children of Concrete

Planners had, on average, a higher level of impairment than the children of Informal Planners (i.e., 3.467 Impairment = Moderate/High Impairment vs. 2.385 Impairment =Low/Moderate Impairment; difference of 1.082).

Two brief vignettes of parental caregivers who took part in this study are provided as exemplars of Concrete Planners and Informal Planners. Following these vignettes, important observations related to concrete planning and informal planning are presented; and factors that were identified as distinguishing between Concrete Planners and Informal Planners are discussed.

Concrete Planner: Sarah

Sarah is a 60-year-old married mother of four children (three boys, one girl). She reported her yearly household income to be approximately $120,000. Her daughter Jessica is 24 years of age, and has a diagnosis of Rett Syndrome. Jessica's disability is such that she requires assistance with all aspects of day-to-day life; as described by Sarah, Jessica "can't do anything independently."

To date, Sarah and her husband have engaged in extensive formalized future planning. They have had one of Jessica's older brothers designated as alternate committee for Jessica in the event of their deaths; they have also obtained commitments from their other two sons that they will continue to play active and engaged roles in Jessica's future life. Sarah and her husband have set up an RDSP for Jessica, as well as establishing a discretionary trust fund. They also have a legal board in place, made up of a mix of family and non-family members. At present, the board's primary role is to administer the trust fund; however, Sarah envisions the board's role, in time, as expanding to include all major areas of Jessica's life: "the board will eventually oversee everything that goes along with supporting Jessica." In this way, Sarah sees the board and her son who has been designated as alternate committee as sharing decision-making, with the understanding that her son would have final say as he is the "most trusted person."

In addition to the more concretized social network afforded by the board, Sarah and her husband have also placed emphasis on developing a strong informal social network around their daughter; as a result, Jessica is very connected and engaged within her community (e.g., volunteer work, outings with friends, an array of recreational activities). Sarah has had discussions with these informal support network members and feels confident that they will continue to play an active role in Jessica's future. A few of these network members have also committed to assisting with particular areas of Jessica's future life (e.g., helping to develop customized employment for Jessica, acting as a mentor or "sounding board" to Jessica's staff).

Sarah and her husband have also engaged in extensive planning related to Jessica's future living arrangements. As a first step in their plan, they purchased a house that they remodeled into an "intergenerational" living environment, in which the family shares certain common areas (e.g., kitchen, living room), but Jessica also has her own separate living space. At the time of her participation in this research, Sarah and her husband had recently purchased another house; with this house, they intended to set up an innovative housing environment for Jessica, which would involve Jessica and others with intellectual disabilities living with typically-abled individuals in a "rich interconnected independent living situation." While Sarah and her husband were still in the process of formalizing this portion of their residential plan for Jessica's future, they had already accomplished important steps in terms of exploring how the house would be managed from a financial standpoint by the board, and they had set timelines within which they hoped to have Jessica transitioned to her separate living environment.

Based on the above discussion, it is clear that despite their daughter's relatively young age, Sarah and her husband have already taken significant steps toward concretizing plans in the three key areas of finances, decision-making responsibilities, and place of residence. In reflecting on why she and her husband have sought to formalize their future plans to the degree that they had, Sarah provided some valuable insights:

> When you have someone like Jessia who's so vulnerable, it's much more difficult to let go. At least it has been for [my husband] and I….As far as planning for her future and stuff, it's just good stewardship. I mean she can't do it for herself and if we don't do it, if we don't put in place the building blocks for her to have a life that is really rich, then it will be whatever it is - whatever someone else decides and I don't really feel good about that…Not that there aren't good people in the world, because there are lots of really good people, but I would much rather that, and we do have, the opportunity and ability to kind of get things put in place while we're still able to do that.

Informal Planner: Hope

Hope is a 53-year-old married mother of two children (two boys). She reported her yearly household income to be approximately $55,000. Her younger son Ian is 19 years of age, and has a diagnosis of Down Syndrome. Hope described Ian as having a fairly low level of impairment, being capable of performing most basic care needs independently (e.g., washing, dressing, toileting), but requiring assistance with more abstract daily tasks (e.g., money management, scheduling).

Hope and her husband have espoused a fairly minimalistic approach to future planning. As explained by Hope, “we’re just avoiding anything we don’t need.” With this in mind, Hope and her husband’s formalized planning has been limited to setting up an RDSP, and establishing a representation agreement in which they designated their older, typically-abled son as Alternate Representative and their family friend as Monitor on the representation agreement. Despite these formal designations, Hope reported that she and her husband have had minimal discussion with their typically-abled son about what his roles and responsibilities as Alternate Representative will be. Moreover, Hope was unsure whether the friend who had been designated as Monitor on the representation agreement would actually remain in this role in the future, and she was open to entertaining other individuals for this position depending on changing life circumstances.

With respect to planning around Ian’s future housing needs, Hope and her husband’s plans are largely informal. Ian currently resides in the family home, and Hope envisions him continuing to live with them for at least the next 10 years. Hope indicated that she and her husband have decided to wait until Ian voices a desire for greater independence before taking steps toward formalizing residential plans. In the meantime, Hope and her husband have begun to consider the types of living situations that they feel would be appropriate for Ian. Currently, they believe that if and when the time comes for Ian to move out, they will likely seek some sort of shared living arrangement that will both meet his needs but also provide him with as much independence as possible. They also believe, however, that they will need to continue exploring housing options as time goes by, based on Ian's changing ability level, in conjunction with the service system's changing service offerings.

Similar to Sarah, Hope and her husband have put a great deal of energy into building relationships with people in their community; which, in turn, has helped to ensure that Ian is a well-connected and valued community member. To date, Hope and her husband have made the decision to avoid establishing a more formalized social network (e.g., microboard, circle of support), believing that the potential benefits of such a network would be overshadowed by the anticipated time and effort involved with establishing and maintaining it. Hope also indicated, however, that she and her husband will continue to explore the suitability of a more concrete social network as their life and Ian's life circumstances change.

When asked to reflect on why she and her husband have approached future planning in a relatively informal and flexible fashion, Hope cited her family's social connectedness, in conjunction with her belief that they will be able to formalize plans on an "as-needed" basis, as being primary factors, stating:

> I think that we have enough of an informal network that should we be struck down tragically that something formal would spring up to support my son. And I think, should something not happen tragically, we are able to see the writing on the wall far enough ahead that we could put something in place if we needed it.

Overarching Observations of Concrete Planners & Informal Planners

The Necessity of Flexibility

The need for flexibility within future plans was an issue that was raised by the majority of parental caregivers in this study, regardless of whether they were Concrete Planners or Informal Planners. With respect to Concrete Planners, parents generally had a fairly clear vision for what they wanted for their child's future; however, they also recognized that they "…can't control from the grave or dementia" (CP1) and that "…the thing you can count on the most is change" (CP9). Concrete Planners, as illustrated by the quotations below, generally recognized that they were simply doing the best they could with the information that was currently available to them, and that, with the availability of new information and services, there was no guarantee that their plans would continue to be the best option for their children:

> Even though I believe that this is the best situation ongoing for [my son], I can't know that. I can't know what society will be like in 40 years from now when I'm definitely not here. So I have to hope…that we have done enough through the community living movement to make society aware that there is a role to play in supporting our people with developmental disabilities. And that's all I can hope for. Otherwise I'll drive myself crazy**.** (CP4)

> It's always going to be a moving target because even if [my daughter's] healthy and she lives to 70 or 80, she is still going to be here another 40 or 50 years. We just don't know if my personal money will enable her to live that long supported through the trust or if she would have to go to CLBC. Nor do we know what the model will be like within government-funded systems, right? It changes every 10 or 15 years. (CP8)

Importantly, in recognition of the inevitability of changing circumstances, the majority of Concrete Planners voiced a desire for those in a position of succession (e.g., typically-abled children, other close family members) to feel comfortable altering plans if it was felt to be in the best interests of the individual with an intellectual disability. As expressed by one Concrete Planner,

> As far as what needs to happen with [our daughter], we think we're making a good decision for her now, but that might not be the best decision for her later…Like where she's going to be living, maybe that's not going to be a good place for her in ten years. So we've left that flexibility open. [Our successors] know what we want for her. (CP6)

Regarding Informal Planners, this recognition of the need for flexibility in the face of unforeseeable future circumstances often appeared to be a primary reason for why these parents had not taken further steps towards concretizing their future plans. As expressed by one Informal Planner,

> Life with [my daughter] has taught me to just do little bits. That you can't go 20 years, because who knows what happens in that time. Who knows what happens with her health. Or who knows what happens with finances or government funding or programs. So we go about 2 years now. It used to be day-to-day. Now we're all the way up to 2 years. We have a 2-year plan right now. (IP8)

As is evident from the above quotation, this need for flexibility often translated into Informal Planners being very present-focused, with less formal consideration for the more distant future.

Some Informal Planners actually voiced a strong desire to formalize plans, but felt that the need to be flexible actually prohibited them from taking such action.

> I would very much like to make set permanent plan, but as you and I both know, life throws you curves, and you just have to go with the flow so to speak. What I would like to have myself do is to write down what [my husband] and I wish for [our daughter] - what we would like her life to look like when we're gone. And we can't write it down, because as [my husband] alluded me to, there's so many different variances… (IP3)

Other Informal Planners felt pushed towards espousing a more informal planning approach after trying, unsuccessfully, to develop more concretized plans around changing circumstances and unknown future events:

> …We've become flexible. We certainly had ideas in the beginning, but they were incorrect for how things were going to be. We had lots of ideas. When we first started out planning we envisioned something quite different than how things turned out….So yeah, I mean, I will freely admit that I've been mistaken over and over and over again.…You have to change your mind about what the future's going to look like…you have to kind of let the future decide how things are going to turn out. (IP5)

Concrete Planning: The Ultimate Goal?

Perhaps contrary to expectations, the data analysis revealed that moving towards increasingly concrete or formalized plans was not necessarily the goal of all parents interviewed in this study. In other words, it was not always the case that those who were identified as being Informal Planners were working towards making their informal plans more formal. With respect to those parents who felt that plans needed to remain informal, two major reasons were cited. Specifically, a few Informal Planners raised the issue of the ethics of creating concrete plans meant to account for the remainder of their child's life. As one parent explained, "…long term, everyone's life can change. I think we'd all hate to have our lives laid out for us for the next 50 years – like, 'this is what you're going to be doing if you are still alive in 50 years.' You want to have some flexibility left for that" (IP8**)**. The other major reason cited were concerns around the potential of "straitjacketing" successors by creating overly detailed and restrictive plans:

> …The world can change. So that's part of my planning. I don't want to throw [my successors] in a straitjacket where they feel they're legally bound to do something, or morally bound to do something, that's no longer going to work. And that's part of the decision of not saying specifically. (IP8**)**

Many Informal Planners did, however, feel motivated to further concretize their future plans. In particular, it was observed that Informal Planners who had children who were still fairly young (i.e., late teens, early twenties) generally expressed intentions of continuing to formalize their plans. For example, one Informal Planner, whose son was 19 years of age at the time of the interview, stated, ""In about 5 years I'm thinking that we will sit down and really get formal about what he [designated successor] might take over if we can't do it" (IP9). Similarly, another mother - with a son also aged 19 years - who had engaged in fairly informal planning to date, expressed her need to move forward with formalizing plans by explaining,

> …If something happens to me, I'm going to have a young man who is gonna be so stressed out and lost for a long time…And I've got to make sure - and that's where I know I've got to do some planning, but it's really hard to plan with uncertainty… I know I need to build. I can't just rely on my family. (IP4)

In this way, there appeared to be a potential dichotomy in Informal Planners, with some Informal Planners having arrived at the decision to create plans that were fairly informal and thus, very flexible; and other Informal Planners being in a state of transition, in a process of moving from informal- to increasingly detailed and formalized plans. With this in mind, it is conceivable that if this latter subset of Informal Planners were to be interviewed at a later point in time, many would then shows signs of much more concrete planning behaviour.

Planning as a Continuous Process

The parents interviewed in this study largely viewed planning for the futures of their sons and daughters with intellectual disabilities as a continuous, and unending, process. As expressed so succinctly by one parent, "Everything is planning. It is constant planning. It's not done. We don't, like, arrive and we're there and we're finished. So it is a continual process. Continual review and planning" (CP7).

Even Concrete Planners who had invested significant time and effort into creating far-reaching formalized plans for their children generally viewed their plans as being works in progress. For example, one parent who had, to date, engaged in very extensive concrete planning explained why she felt her planning for her daughter's future would never be complete, stating,

> …As you learn more, you alter things to make the most of what your planning is….You just have to change when things change. Like four years ago there was no such thing as an RDSP, but now there is. So of course you take advantage of it if you can. (CP9)

Another Concrete Planner related future planning to the building and renovating of a house, and, in so doing, provided a powerful illustration for why the planning process is one of continuous development and revision:

> I think in planning you've got some pillars. And they're valuable - pillars create a foundation. So you're building a foundation of a house. Some things you know - financial planning, making sure your will is in order, relationships are important, being part of community, people who know your son or daughter. So those are your pillars, but then how the house looks or renovations you might do to the house are the creative end…It's like you build a house, you paint it one colour but, a few years later, a new colour's in style; it doesn't mean you don't change it and repaint or remodel. (CP7)

Based on the analysis, it appears that the ultimate goal of planning is not to be "finished" planning but, rather, to have developed plans - whether they be formal or informal – to a point where the parent believes that the individual with an intellectual disability will not be unduly negatively impacted in the event of their parent's death or illness. As two parents explained,

> I've done the best I can. My daughter and I are extremely close. I think she will really miss me when I'm gone, but all this other stuff is set up. There's as little damage as possible. Everything will be good. (CP9)

> I'd have to say we're fairly well along. I mean if I did get run over by a bus tomorrow, or hopefully win the lottery or something like that, [our daughter] is taken care of. And I can't begin to express what a relief that is. (CP10)

Factors Identified as Distinguishing between Concrete Planners and Informal Planners

Through the data analysis, seven factors were identified as potentially distinguishing between Concrete Planners and Informal Planners – namely, 1) the parent's socioeconomic status (SES), 2) the level of impairment of the individual with an intellectual disability, 3) the ages of the parent and of the child with an intellectual disability, 4) the parent's involvement with and perceptions of the formal service system, 5) the parent's marital status, 6) the degree of involvement of typically-abled children, and 7) the degree of social support experienced by the parental caregiver. Each of these factors will be discussed in detail below, including the ways in which they appear to support concrete planning and informal planning. Where relevant, the demographic information regarding Concrete Planners and Informal Planners will be related to the qualitative findings.

Socioeconomic Status (SES)

The average yearly household income was $104,615.38 for Concrete Planners, and $58,230.77 for Informal Planners. In line with this finding, the qualitative data analysis also suggested that high SES (i.e., a yearly income ≥ $100, 000) is associated with concrete planning, and lower SES (i.e., a yearly income ≤ $60,000) is associated with informal planning.

High SES: Concrete Planning

Through the data analysis, it was observed that high SES appeared to support concrete planning in a couple keys ways. Most prominently, high SES appeared to support developing concretized residential plans, as high SES parents were more likely to be able to create residential plans that appealed to them. In particular, parents with disposable monetary resources were able to customize their residential plans, rather than simply planning around government-provided options (i.e., groups homes, home shares) – options about which many parents in this study voiced concerns (see Part 3: Suggestions for Improving the Future Planning for more information). With the ability to customize residential plans, many high SES parents had purchased or were planning to purchase a separate home for their children with intellectual disabilities, which they generally viewed as being their child's "forever home." The following statements made by one high SES parent effectively illustrate how having financial means enabled her to develop fairly innovative, far-reaching, residential plans for her daughter:

> The property that we bought is a fairly good size and we're lucky because we've had a good income coming into our home. So we're not just relying on funding from CLBC…We will need good funding from them and we do have some already, but certainly I don't have to raise the money….So, we can kind of move ahead with what we are envisioning. And we have a really great network of people who are really excited about the idea. Young people who want to live in a different kind of way than what's been sort of the status quo. They're looking at alternative ways of living…Not just [my daughter] will be the only person living with some sort of challenge…We would like her to be able to include some of her friends in her household if that's what she would want, and I think that's what she wants, along with other people who don't have those same issues. (CP1)

Perhaps not surprisingly, high SES also appeared to support the development of very extensive and formalized financial plans, primarily due to parents' concerns surrounding their child's heightened risk for financial abuse. In this way, parents with more monetary resources had generally tried to create financial plans that had multiple financial safeguards built into them. At the same time, these formalized financial arrangements also often translated into fairly concrete planning around decision-making responsibilities, as parents provided designated trustees, and often anyone else potentially connected to their child's financial future, with clear guidelines around how various circumstances should be handled. This extensive financial safeguarding is very apparent in the following quotations, which were made by a particularly affluent Concrete Planner who participated in this study:

> I've also made sure in my will that my niece and my nephew get, they get money from my will if I die, but it's not in any way attached to my daughter's trust so that they won't be stingy in using the trust because they benefit in the end. If there's any money left from my daughter's discretionary trust or from her Registered Disability Savings Plan, it goes to [a particular society]. (CP9)
>
> I like the idea of having…three [trustees], so that two of the three need to agree. Like, if they decide in the future that maybe [my daughter] should own her own place instead of having the subsidized housing, then two out of the three have to agree on that, then use her discretionary trust fund to purchase it….I also have an investment that I've put my sister on. It's my money in there, but if I die it goes to her and it's to take my daughter on a holiday…And my sister has signed, I forget what's it's called, but basically a declaration saying that that money is only to be used for the benefit of [my daughter]. So she can't decide to remodel her house with it or something. (CP9)

Finally, high SES also appeared to support concrete planning in the sense that parents with financial means were able to use their monetary resources to help ensure that the formal plans they were creating would actually be enacted. For example, one high SES Concrete Planner made the decision to endow funds to a particular society that she viewed as playing an instrumental role in her daughter's future. In explaining her reasoning for setting up the endowment, this parent stated, "…I feel that that connection to [Society's name] and the support I give them will be reciprocated in their care of my daughter" (CP9), clearly illustrating that this parent felt that her monetary donation would help ensure the society's continued involvement with her daughter when she, the parent, is no longer around to advocate for her.

Low SES: Informal Planning

The data analysis also highlighted how low SES relates to informal planning. In particular, as illustrated by the following quotation, for low SES parents, planning was very contingent on services made available through the formal service system (e.g., publicly funded housing options – i.e., group homes, home shares, day programs, etc.).

> One thing that might be a factor is although we're not really, really poor, we don't have a lot of assets; they're limited. We're very dependent on the government and the supports they're going to provide. So I think that to some extent limits our…planning - whereas a wealthier family might be able to set up more things. (IP8)

With this in mind, parents who felt that the available services were not appropriate for their children, but who also lacked the financial means to effectively customize their future plans, often engaged in much more informal planning in order to avoid creating what they perceived to be "poorly fitting" concrete plans. This reluctance to concretely plan around inappropriate formal service options is clearly reflected in the following statement made by one low SES parent in this study:

> …The current options are not even close to what I would consider for my daughter. And that's also why I'm not making any firm plans because there's nothing out there that I can even remotely see as something that I would want me daughter to be in. (IP7)

Limited financial means also appeared to encourage parents to adopt more of an informal, "wait-and-see" approach to planning. As illustrated by the following quotation, this "wait-and-see" approach related to watching for service options that might become available at a later point in time:

> Hopefully it will be way into the future when I'm not involved, and who knows what kind of models will be available for funding. We're heavily

> reliant on government funding - I guess you can tell that - so I'm still looking at what they can come up with. (IP8)

This approach also extended to parents waiting to see whether their own personal circumstances might improve to the extent that they would eventually be in a position to develop more personally appealing concrete plans for their children. This wait-and-see mentality is very apparent in the following statement made by one Informal Planner of lower SES: "You know, one of my plans is so lame – like, hopefully I'll win the lottery or one of these houses and I'll build a place and he'll have a little suite in it" (IP11).

Level of Impairment

Level of impairment was operationalized on a 5-point rating scale, with "1" being "Very Low Impairment," and "5" being "Very High Impairment." The average level of impairment in the individual with an intellectual disability was 3.467 for Concrete Planners, and 2.385 for Informal Planners, indicating that the children of Concrete Planners, on average, had a higher level of impairment than the children of Informal Planners. The qualitative analysis also highlighted this potential association between level of impairment and planning behaviour.

High Impairment: Concrete Planning

A high degree of impairment in the individual with an intellectual disability (i.e., a "4" or "5" level of impairment in the 5-point rating scale) appeared to encourage parents to engage in concrete future planning in three key ways. First, with a more highly impaired child, many parents in this study did not feel able to rely more informally on family members and friends to be involved in their child's future; which, in turn, appeared to push parents towards more concrete forms of planning. This sense of feeling unable to informally rely on close others for the present and future care needs of the individual with an intellectual disability is very apparent in the following quotations:

> We [would] ask friends if they would take [our daughter] for a few hours and it just never worked out. And part of the thing that we had to come to grips with was that…it's one thing to ask people to take a sweet, well-behaved child – well, [our daughter] is sweet - but a well-behaved child…It's quite a different thing to ask them to take a child who's not toilet-trained…that you can't communicate with because she uses sign language. That may throw tantrums, and [our daughter] will strip when she's very, very distressed. You know, so we had to deal with the reality of who [our daughter] was…and make plans that fit that. (CP13)
>
> You find out who your friends are when you have a child with a disability. Even girlfriends. You'll have girlfriends who have been your girlfriends all your life, and then you have this baby with severe disabilities and you say, "Can you babysit for me one night? My husband and I want to go to a movie." "Oh [participant's name], I don't know how to say this but I don't want her seizuring on me, I'm afraid. I'm nervous. Blah, blah, blah." (CP12)

Second, many parents in this study who had children with a high degree of impairment appeared less confident that certain important elements (e.g., social engagements, recreational activities, etc.) would naturally occur; as a result of these concerns, and as is apparent in the following quotations, it appeared that these parents felt motivated to create concrete plans as a way of ensuring that these important elements would continue to be a part of their child's life in the future.

> [My daughter's] not able to go out on her own. She's not able to sort of engage in activities on her own, so I need people who will keep in touch with her. I mean the arrangement that Lifetime Networks Victoria has…they will set up formal networks whereby they get together every few months. That sort of thing will probably be the formal part of [the plan]. (CP5)
>
> …One of the challenges for [my son] is that everything has to be facilitated. He doesn't have the ability to call someone or to invite someone over to his house. Or to walk up the street to someone and get to know them…It relies

> more on a facilitated role for relations and connections…Even if [my son] had a friend, he has to rely on someone else to talk with them on the phone, or to invite them over, or to get him to somewhere. (CP7)

Finally, third, having a child with a high level of impairment also seemed to support concrete planning in that many parents felt that the severity of their child's impairment required them to create comprehensive, concrete plans as a way of protecting both their child with a disability, as well as those individuals in a position of succession. In other words, it appeared that parents in this study equated a high level of impairment with a high degree of risk, and, in turn, felt pulled to create plans that adequately addressed this risk-potential. This sense of feeling responsible for creating plans that would protect future caregivers, as well as the individual with an intellectual disability, is very evident in the statements made by one Concrete Planner:

> [My daughter] self-abuses, she's aggressive…We have a responsibility there to not place other people at risk. And she will grab at steering wheels and she will be aggressive in cars, so it's not safe for her to go in the car with just anybody…So, you know, those things had a significant impact on all of our decision making. We have to be responsible to the community; we have to be responsible to [our daughter]. We have to deal with where [our daughter's] at, and where friends are at, too, in terms of their level of support. (CP13)

Low Impairment: Informal Planning

There were several ways in which low impairment level (i.e., a "1" or "2" level of impairment in the 5-point rating scale) appeared to be related to informal planning in this study. To begin, a few parents who had adult children with low levels of impairment voiced concerns over the appropriateness of available services for their children. Specifically, these parents felt that their children were too high functioning for many service options; which, in turn, appeared to push parents towards more informal planning approaches. This idea of informal planning in response to feeling that formal services options are a poor fit for high functioning individuals is evident in the statements made by one mother when asked whether she was planning to make use of concrete social network planning services (i.e., Vela Microboard Association): “I think [my daughter] is too independent for that to really be applicable for her…I like that kind of approach, but I’d do it more informally…” (IP7). Similarly, another Informal Planner with a relatively high functioning son related the informal planning she and her husband had done around her son’s future housing needs to the fact that they did not feel that there were suitable housing options available, explaining, “If he was still living with us at 30, it probably won’t be in either of our best interests; however, he's 28 now and I can see that that might be a movable date just because, you know, there may not be anything out there” (IP2).

Having a child with a low level of impairment also appeared to translate into future planning being more dependent on the personal wishes of the individual with an intellectual disability. This, in turn, seemed to cause parents to engage in more informal forms of planning as they sought to create plans that were flexible enough to respond to the individual with an intellectual disability’s changing wishes and preferences. For example, one mother, when asked whether she and her husband planned to give their designated successor specific guidelines for son’s future care, stated, “No, no, we wouldn't do that. No, [our successor] knows [our son] well enough, and [our son] will tell him if he is displeased with what he is doing” (IP10).

This reliance on the preferences of the individual with an intellectual disability also appeared to contribute to more informal forms of planning as some parents felt unable to move forward with more formalized planning in the face of resistance or confusion on the part of the individual with an intellectual disability. For example, one mother who had a son with a low level of impairment explained the challenges she faced in moving forward with planning, stating,

> He kind of thinks we're conspirators a lot of times. He's quite paranoid, even with us. He knows we love him but he doesn't always think that what we're doing is in his best interest…so yeah… any time he feels his control slip away he puts lots of barriers up. (IP2)

A low degree of impairment also seemed to support informal planning as parents generally had fewer concerns about burdening close others; which, in turn, caused them to be more comfortable developing plans that relied largely on the informal involvement of family members and friends. This potential connection is clearly illustrated in the exchange that took place between the interviewer and one Informal Planner in response to being asked whether she felt she would have been comfortable developing plans that relied as heavily on her typically-abled son as her current plans do, if her son with a disability had a higher degree of impairment:

> **Participant:** I would not want to burden my eldest son with that. If my son was less abled, wheelchair-bound, required daily care for personal activities of daily living and that sort of thing, that would be a whole other ballgame.
> **Interviewer:** OK. You would need more formal services?
> **Participant:** Formal services, formal support, government intervention. Yeah. Absolutely. (IP9)

Finally, a low level of impairment also appeared to be associated with questions around the level of independence capable of being achieved by the individual with an intellectual disability (i.e., would the individual eventually be capable of living entirely independently?). These questions, in turn, appeared to encourage parents to plan more informally in order to account for potential changes in their adult child. This sense of informal planning in anticipation of potential gains in daily functioning is evident in the statements made by two mothers of sons with relatively low levels of impairment:

> I just don't really see [my planning] as concrete because I just think as [my son] takes more responsibility and he does more, if I can get him to do that, I think he has a potential to be pretty independent. (IP11)
>
> As a parent, when you've lived with someone for years, you might underestimate them somewhat. I think perhaps I do in some ways. When [my son] is 35 he might be ready to live on his own. Who knows. (IP2)

Age of Parent/Child with Intellectual Disability

The average age of Concrete Planners in this study was 59.600 years, while the average age of Informal Planners was 54.769 years. The average age of the individual with an intellectual disability was 28.4 years for Concrete Planners, and 23.538 years for Informal Planners. Therefore, on average, parents and children with disabilities were substantially older in the Concrete Planners group, as compared to the Informal Planners group. This trend was also observed in the qualitative data, with older age in parents (i.e., being ≥ 60 years of age) appearing to be associated with concrete planning, and younger age in parents (i.e., being ≤ 55 years of age) appearing to be associated with informal planning. In addition, older age in the individual with an intellectual disability (i.e., being ≥ 30 years of age) appeared to be related to concrete planning, and younger age in the individual with an intellectual disability (i.e., being ≤ 22 years of age) seemed to be associated with informal planning.

Older Parent/Child with Intellectual Disability: Concrete Planning

Being an older aged parent was identified as potentially supporting concrete planning. Most prominently, many older aged parents appeared to be engaging in concrete future planning because of the belief that, due to their advanced age, they may not be in a position to provide care and/or to oversee their child's care in the not so distant future. This sense of urgency around the need to formalize plans due to aging was very apparent in many of the statements made by the older parents who participated in this study; the following quotations are a few examples of this apparent relationship:

> What pushed us to make more forms of concrete planning is that we don't want to be responsible forever. And we also know we are in our 60s and we aren't going to be here forever. And so that pushes us to move faster. As fast as we can…So we are pushed because we feel we are on a clock and my husband and I are both very close to retirement. (CP15)
>
> We're trying to look at every way possible to have a smooth transition down the road because I am 65 now, and my wife is 62, and we're not getting any younger. So we're just trying to hope a panic situation doesn't happen down the road if something happens to us. So that's what we're working toward. (CP3)
>
> …We're almost 70, well my husband is 70. We can't be doing this forever. So the sooner the transition occurs - there will obviously be glitches, so we can help with the glitches; and once we actually have to step out, hopefully a good process will be in place. You know, a good solid overall plan will be in place. (CP4)

Many of the older aged parents in this study indicated that they were finding it increasingly difficult to manage the physical demands of caring for their children with intellectual disabilities. For example, one mother, in talking about the physical care she routinely provides her adult daughter, stated, "physically, I can't do this anymore. I can't lift my arms, they were pulled out of wherever they get pulled. And

I'm like 'oh my God, I'm getting old!'" (CP11). Similarly, another parent, in talking about her daughter's physical care needs, shared,

> I was trying to get her out of the bathtub…and my back went one night…I'm lying there on the floor bawling my eyes out. My husband comes home, [my daughter's] still sitting in the tub, and I'm going like, "I can't do this anymore…What if I was here by myself?....I can't do this anymore! I'm getting older." (CP12)

This realization of age-associated physical limitations and vulnerabilities – potentially exacerbated by the long-term physical care provided by many parents - appeared to encourage parents to move toward formalizing plans, as illustrated by the statements made by one older aged parent in this study:

> ...When I sort of hit around 55, it kind of hit me… First of all, I'm too tired to do everything. I know that I need to offload some of the responsibility. I mean, as you age, your reserve of mental energy and physical energy gets smaller and smaller…You need to [offload], so that things don't deteriorate to a mess. Like if I want to live longer, I have to look after myself; therefore, I have to make a better plan. (CP4)

Being an older aged parent of an individual with an intellectual disability also meant that many of these parents appeared to have spent more time considering future planning options, as compared to their younger-aged cohorts. As is evident from the following statements made by two of the older participants in this study, this increased time spent considering future planning options often translated into the development of plans that evolved in terms of their level of complexity and formalization in order to meet the needs of the individual with an intellectual disability:

> …A few years ago we created sort of a mini-apartment in the family home so that [our son] got used to idea of the separation. And then approximately a year and a half ago he moved out of our home, the family home, into his home, which is actually a town house. (CP4)

> My daughter actually moved out on her own five years ago, so until that time she lived at home but we were talking about planning for her future...I had originally thought a group home was the answer and my daughter refused to move into a group home. She has friends in group homes and that wasn't what she thought of as what she wanted. Then we talked about home share, which I wasn't really comfortable with; she has a family and she doesn't need a second family. But anyway, she decided - what she just said [was] "I want my own place." So we were all like, "OK, how's that going to work?"…We decided that because that was what she really wanted, that was what we were going to plan for. That was her dream and we were going to honour it. (CP9)

Finally, being an older aged parent also appeared to be associated with concrete planning behaviour in that, developmentally, older parents are reaching an age where they are more likely to want to retire and/or to engage in more leisure activities or commit more time to personal care. As illustrated by the following quotations, this desire to be able to dedicate more time to later-life activities appeared to encourage some parents in this study to formalize future plans:

> We want to make sure that we have everything organized so that when we step out, due to not being here any longer, or [chuckles] enjoying life and retired, that it will be easy for everything to keep continuing. (CP15)

> …My husband and I hadn't had a vacation together in 25 years. On our 25th wedding anniversary we thought we'd go to Mexico for a week… it's like you need a life yourself too… You spend your whole life 24/7 looking after this person. You do. And now that [my daughter's] moved out of the house it's kind of like "holy shit, we've got our life back." (CP12)

With respect to the aging of the individual with an intellectual disability, older age appeared to be associated with concrete planning in that having an older aged child with an intellectual disability potentially forced parents to confront the likelihood that their child would outlive them, and thus, would require plans to be put in place for the post-parental care phase of their life. This idea is clearly reflected in the statements made by the mother of a 36-year-old woman with an intellectual disability:

> …Often kids with higher disability needs, a number of them would pass away kind of in their 20s or 30s, and then if the kids get through their 30s, they're often healthy enough [that] they're going to live a long life. So those of us who have kids kind of in the mid-30s, we're all kind of realizing, "ooh, this is going to be long-haul," and the strong reality that we're probably going to be outlived by our kids… So in terms of doing anything formal, it's really been probably the last ten years I've concentrated the most on it. (CP8)

This same mother also pointed out that, with the older age of her daughter, she felt she had a much better understanding of her daughter's abilities than when her daughter was younger. With this richer understanding, this mother felt that she was in a good position to be developing concrete plans, stating, "With my daughter being 36, we're really at a place of knowing what her abilities are and the areas where she needs help" (CP8).

Younger Parent/Child with Intellectual Disability: Informal Planning

Being a younger-aged parent of an individual with an intellectual disability appeared to be associated with informal planning in that younger parents' generally believed that they would be in a position to continue providing care to their child with a disability for many years to come. As illustrated by the following quotations, this belief in their own ability, and desire, to provide long-term care often led parents to feel that formalizing plans was not currently necessary and/or a good use of their time.

> I think it's a bit early to do formal planning. We see ourselves as taking care of him for another 20 years or so, so I don't see spending a lot of time on that yet. (IP1)

> I'm healthy right now and I envision being part of [my daughter's] life, probably, for at least 20, 30 years…I don't think I would be willing to give up

> that control until I actually felt unable to do it…We sort of talked about backup plans, because we're all mortal, but what I'm sort of relying on is [that] I'm going to be here and involved in her life for another 30 years. (IP8)

> There's gonna be a day that I won't be able to look after [my son] anymore, but I'm hoping that's going to be a really long time away, like when I'm in my 80's and finally go, "Ah, maybe it's time he needs to move out." (IP4)

Within British Columbia, individuals with intellectual disabilities transition from child services to adult services at the age of 19 years. With this in mind, parents who participated in this research who had younger adult children with disabilities (i.e., 19 or early 20s) often were so focused on navigating this transition, and on getting their child connected with supports and services that they needed in the present, that little time and/or energy was left to think about the more distant future. This connection between the recent transition to adult services and informal future planning behaviour is very apparent in the following statements made by two mothers who both had children who were 19-years-old:

> I haven't really thought about [formalizing plans]…We're just coming through transition to adulthood so we haven't really got much further than that yet... we're just kind of sighing that we're through now. So we're kind of resting for a while and then thinking about the rest of it. (IP9)

> As a parent of a child with a disability, it's only when you're older that you actually even have the time to [plan]. There's so many thresholds that you have to cross, especially when your child leaves school, to set up for after school life. So that keeps you busy for a while. (IP7)

Parents' Involvement with & Perceptions of the Formal Service System

High Involvement/Positive Perception of Service System: Concrete Planning

High involvement with the formal service system and/or the disabilities community appeared to be related to concrete planning in a number of ways. Parents who reported having a high degree of involvement with the formal service system - through such avenues as their chosen careers, advocacy work, other volunteer activities – appeared to have extensive knowledge of the service system, including the types of services that are available, the way in which services can be accessed, and potential future changes to the service system. In fact, as is evident from the following quotation, some parents intentionally became involved as a way of equipping themselves with, what they perceived to be, needed knowledge:

> To understand CLBC better - because it was a whole new animal - I did some research, but they also have community councils. Like they set up volunteer community councils, so I applied to be on the [Community's Name] Community Council, and I'm now actually chairing it. So that was part of my homework to learn the system better. It's easier to learn from within than from the outside, so that's what I did. (CP9)

The information gleaned from years of high involvement with the formal service system appeared to assist parents in moving forward with developing comprehensive concrete plans; in particular, these parents generally had a greater understanding of a range of planning models, the areas that needed to be addressed in their planning (i.e., housing, finances, decision-making, recreational/ socioemotional needs), and how to go about accessing the services and supports upon which that their concrete planning relied. The following statements illustrate this apparent connection between having extensive knowledge of the formal service system and formalized planning behaviour:

> I worked with Planned Institute actually; I was in the education part and I did presentations and stuff with parents. I would give presentations to the parents, so then I would need to learn about what these topics were, so things like housing, wills, trusts, estates, and microboards – Like, I gave presentations on all that stuff…I learned an awful lot about what I needed to do. (CP6)

> I worked in the field for 25 years. I'm a social worker and I was Director of Programs and Quality Assurance with [Organization's Name], an organization

> for people with disabilities….We're members of PLAN. You know, I've known about PLAN's work since the beginning….I'm chair of [Community's Name] Committee Council now. So we've always been very, very, very involved in the field….I think we've just have always followed everything very closely that has to do with people with disabilities. We're well aware of [future planning] options. (CP13)

High involvement with the formal service system also appeared to be related to concrete planning in that some highly involved parents indicated that they felt their connections with the service system helped to make more desirable future planning options available to them; which, in turn, likely acted as an incentive to further formalize plans. By way of an example, in talking about the way in which her connections to the formal service system aided her in developing future plans for her daughter, one highly involved Concrete Planner related the following experience:

> [My daughter's] on the waitlist to get into an apartment building. There's about 30 on the waitlist and I've made sure she's the first one on the waitlist. And that's my connection to [Society's Name]. I'm actually very much a part of the building, the construction of this building, so I see all the facets. So I got a copy of the waitlist from the person who is in charge of programs… And my daughter was about number eight and I said, "How come [my daughter's] #8 on the waitlist? I thought she'd be #1 on the waitlist." And about an hour later the waitlist came back to me and she's number one on the waitlist. (CP9)

Prolonged engagement with the formal service system led many parents to have a greater understanding of what can happen to a person with an intellectual disability when clear planning has not been put in place. For example, one mother, in talking about what she had witnessed through her years of working in the disabilities community, related one particularly haunting experience,

> I was working in the community and I was supporting a family - the parents were in their mid-70s and they had two children. It was a boy and a girl and both children had Down Syndrome... [the parents] had their children living at

> home with them…. When the parents died, which was inside of a year of each other, the brother and sister were separated and put into it whatever was available…It was awful, it was really traumatic for them, it was horrid... And as [Daughter's Name] mom, I don't want that to happen to her. (CP1)

As is clear from the above quotation, this understanding of the potential harm that can befall individuals with intellectual disabilities in the absence of adequate planning appeared to push parents in this study towards formalizing their plans for their children.

Parental long-term engagement with the formal service system also often led to the development of longstanding relationships with other parents of children with disabilities. Beyond providing valuable fellowship opportunities, these relationships also appeared to be important in terms of providing opportunities for parent-to-parent support and guidance with respect to planning. This idea is clearly reflected in the statements made by one parent as she explained how her relationships with other parents assisted in her own future planning process:

> Planning has always been huge…And I've been very connected with many families over the years. And that's really been helpful too, just to walk the walk with people who live and breathe this stuff. Even though all our kids' needs are different, we're all on the same journey…. (CP8)

In this way, parents in this study were frequently able to learn from other parents as they took steps toward formalizing their plans.

Finally, involvement with the formal service system also appeared to be related to concrete planning in that having had positive experiences with the service system sometimes served as a useful entry point for parents when developing concrete plans. For example, one father explained how having had positive experiences when his daughter received respite care at a group home facility was instrumental in his wife and him later developing concrete future plans which centered around his daughter residing in a group home. As this father explained,

> We were fortunate in working with CLBC that they provided us with an introduction to group homes. Because [our daughter] would go to a group home about a kilometer from here, I think it was two nights a week…And [she] adored going there. She loved the staff and so forth, so we saw that, "gee, this is something that's going to work." (CP10)

Limited Involvement/Negative Perception of Service System: Informal Planning

Low levels of involvement with the formal service system appeared to be connected with informal planning in a couple key ways. Most prominently, parents who indicated having low levels of involvement with the formal service system often spoke of a great deal of confusion and frustration when trying to move forward with their planning. These feelings of confusion and frustration are clearly evident in the statements made by some of the parents in this study who appeared most uninvolved with the formal service system:

> It's overwhelming for me. I just get overwhelmed with [planning]. I get in and I read all the stuff and it's just like ,"OK, now what do I do?" I set it all aside, and I'm going to do this, and I'm going to do that, and I just don't get it done. (IP11)

> It's really hard to get answers and hard to track down who you are supposed to talk to about anything….Really hard to get hold of anybody that is not a machine. You know what I am saying? Like, if you phone the Ministry for instance, I don't even know who to phone anymore. (IP6)

Perhaps understandably, this sense of confusion and frustration seemed to translate into informal planning behaviour for two primary reasons – 1) parents were so focused on trying to sort out how to access presently-needed supports and services that they did not have the time or energy to think concretely about the more distant future; and 2) parents lacked the knowledge needed to access the supports and services upon which concrete planning often relies.

Limited involvement with the formal service system also appeared to have the effect of some parents envisioning futures for their children comprised of services that are, in actuality, no longer available or very difficult to access (e.g., group homes). This inability to access desired, but unavailable, key services caused some parents to have to discard the plans they were in the process of creating and start anew. Having to restart the planning process caused these parents to have plans that were significantly more informal than parents who had been developing their plans for extended periods of time. This idea of having limited plans in place as a result of having an incorrect understanding of available service options is clearly reflected in the statements made by one Informal Planner:

> …Right up until my first interaction with CLBC, I thought [my son] would…eventually go into a group home. But at the first meeting they told us parents that a) we probably wouldn't get any funding, and b) they were no longer funding group homes because they were starting to close them. So you go for 17 years thinking you have a plan and then you have to start all over again. (IP1)

Finally, having a negative perception of the formal service system also appeared to be associated with informal planning. In particular, several of the parents in this study spoke to a high level of distrust for the formal service system – for example:

> I don't trust the government system anymore. I think if there was a desperate situation they might come through in a timely fashion, but I think that they are just not supplied with the resources and the staff to do the job that needs doing… And I just don't trust it. (IP9)

> A lot of [service] people I deal with don't care; they're just doing a job, unfortunately…I had five different social workers that I had to deal with and

> not one of them ever gave me the feeling that they cared about my son or what we were going through …So when you're in a situation like that it's very difficult to trust or even talk about what you need. (IP1)

In light of these feelings, it is, perhaps, not surprising that these parents found it preferable to develop primarily informal plans which relied largely on the involvement of family members, friends, and the broader community; as opposed to developing plans that relied more heavily on the formal service system.

Marital Status

The qualitative data analysis highlighted the possibility that marital status may be associated with planning behaviour. In particular, the data analysis suggested that being married is related to concrete planning, and that being divorced is related to informal planning. Importantly, the demographic data relating to Concrete Planners and Informal Planners present a similar picture: In the Concrete Planners group, 12 parents with married, and 3 parents were single (2 parents divorced, 1 parent widowed); in the Informal Planners group, 6 parents were married, and 7 parents were single (6 parents divorced, 1 parent widowed).

Married: Concrete Planning

Several of the married parents who took part in this research highlighted the potential association between being married and concrete planning. In particular, married parents often felt that having a spouse enabled them to share the "planning load" with someone, thus providing important opportunities for shared brainstorming and decision-making around the form that future plans should take. In turn, these parents often voiced a great deal of satisfaction and/or comfort with the plans they had developed, as they had the assurance of knowing their plans had been “vetted” by someone (i.e., their spouse) who had a comparable degree of knowledge regarding the needs and wishes of the individual with an intellectual disability. This connection between being married and concrete planning is very evident in the statements made by one Concrete Planner as she reflected on the things that had assisted her most in moving forward with formalizing future plans for her daughter:

> I think, number one, I'm not a single parent. There's two of us that are here that are working on this [planning]. I think being alone and having to do all this - I mean, it's overwhelming for the two of us to have to do this - but somehow having two of us here to talk to, to bounce things off… no matter how crazy they are. I mean, we've been married for 30 years and we've had this daughter for 20 years - like, we can talk about anything. And I think that has helped us to keep each other in check too. We have this plan and we need to work towards it, but there's someone else to help me. (CP6)

Being married also appeared to enable parents to move forward with concrete planning in the sense that married individuals were generally able to share day-to-day tasks and responsibilities with a spouse, thereby increasing the likelihood that these individuals would have sufficient time in their daily lives to put toward developing future plans for their children with intellectual disabilities. One Concrete Planner, who was single throughout her daughter’s childhood and early adulthood but then remarried, very effectively spoke to how being remarried, and thus having someone with which to share life tasks, enabled her to move forward with developing plans for her daughter:

> I was a single mom, my ex-husband and I separated when I was 29 and I didn't remarry until I was 46, so I was really busy just being a single mom, working full time - you know, just living. So I didn't have time to really think too hard about [planning]. When I remarried at 46, things got a heck of a lot easier. There's a second income in the family, my husband is a very good bread winner, so things got a lot less stressful and I had more time to think about planning for my daughter. (CP9)

Finally, a few married parents also related their decision to develop concrete plans to their desire to have more quality time with their spouse. In other words, some parents felt that formalizing plans, particularly with respect to their children's housing needs, would enable them to have more time available to spend with their spouse. For example, one mother, in explaining her and her husband's decision to purchase a house for their daughter with an intellectual disability, stated,

> …Since [our daughter's] been at home, well, we've never gone for longer than a week's vacation. Ever. Because we have nobody to look after her and we can't really travel with her. So, you know, we're looking forward to maybe having a vacation together. (CP14)

Divorced: Informal Planning

Being divorced was identified as potentially relating to informal planning. Some divorced parents highlighted the increased challenges of developing plans for their children with intellectual disabilities without the support of a partner. For example, one recently divorced Informal Planner spoke to the ways in which having a spouse might aid her in moving forward with developing plans for her son:

> It would be a lot easier if I had a partner in my life. Because you would just have somebody to share that responsibility [planning] with on a daily basis… And just have somebody with those skills to help you with writing that plan and doing the things that you're not really capable of doing. Helping you….navigate that. **(**IP11)

Other divorced parents spoke to the challenges of trying to negotiate the planning process with an ex-spouse; highlighting how moving forward with formalizing plans can be particularly slow going when ex-partners have disparate visions for their child's future. One divorced father who was struggling to develop formalized residential plans for his child very effectively illustrated this issue:

> My ex-wife…sees things a little bit differently. She sees where one or more nannies would be involved in one or both of our homes…I don't think that is what [our daughter] will end up wanting….[my ex-wife]…would like to see as much care for [our daughter] as possible, but her assessment of [our daughter's] capabilities is lower than mine. I think [our daughter] is more capable, she thinks [our daughter] is less capable. That's really where we have the largest difference. (IP13)

In this way, some divorced parents appeared to be "stuck" with informal plans, in the absence of being able to reach a compromised shared vision with their ex-partner for the future of their child.

Still other divorced parents highlighted the difficulty of formalizing future plans when they harbored serious concerns about their ex-partner's involvement in their child's future life. In other words, some divorced parents felt that they were in a difficult position with respect to planning, as they felt that if they formalized future plans they should, realistically, include their ex-partner in the plan (i.e., designating the ex-partner as the person to assume responsibility for the individual with an intellectual disability in the event of the primary parent's death); however, they also felt uncomfortable with the idea of their ex-partner potentially playing an important role in their child's future. In this way, it appeared that some parents preferred to keep plans informal, as opposed of developing formalized plans with which they felt uncomfortable. This sense of unease around including an ex-partner in future plans is apparent in the following statements, made by two of the divorced Informal Planners who took part in this study.

> I do worry about [the future]…. because then [my son's] father would be involved again and he's a bit of a jerk and I don't really want [my son] living with him, so it raises a whole other issue, right?...Like I don't mind [my son] being involved in his dad's life as far as going there for a weekend or something like that, but, seriously, I don't want him living with his dad… (IP6)

> …You know, it is a concern that if something happens to me and [my son] lives with his dad, will his dad take over that responsibility properly? I like to think that he would but [my ex-husband] is more controlling – like, he doesn't really listen. (IP11)

Informal planning also appeared to be associated with divorce in the sense that parents who had engaged in formal planning with their partner prior to divorcing, potentially had to reevaluate their plans and/or to restart the future planning process post-divorce if plans were no longer seen as being appropriate. This issue was most apparent with one divorced Informal Planner who had started the process of developing a formalized social network with his wife prior to their divorce. As evident in the following quotation, post-divorce, this father was in a position of having to start the planning process anew as he no longer felt the social network was feasible:

> …Our marriage fell apart…The [social] network has kind of fallen apart….it's in a place of indecision and some awkwardness, I'd say….So, I'm not really sure how to go forward with that - whether I'd be able to navigate that in a way that would be positive. (IP12)

Finally, divorced parents - particularly more recently divorced parents - were often in a period of serious transition, and thus, were sometimes very unsure of how their own futures would unfold. As a result, some recently divorced parents appeared less likely to be engaged in concrete planning, as developing concrete plans around such elements as where their child would live and who would be involved in their child's life seemed very challenging in light of their own uncertain futures. This difficulty formalizing plans in the face of changing life circumstances is very apparent in the statements made by one recently divorced mother as she reflected on the challenges of developing formalized plans in light of her own uncertain path: "I'm not even sure whether we're going to stay in the same country, so I'm not sure whether [my daughter's] other support networks are going to stay the same. All that might be subject to change, right?" and, "My situation changes and for me to hand over anything to an organization like PLAN isn't going to work out if I don't even know what continent [my daughter] is going to be growing old on" (IP7).

Degree of Involvement of Typically-Abled Children

Twenty-five of the 28 parents who were interviewed had, in addition to their child with an intellectual disability, typically-abled children. While the vast majority of parents in this study had typically-abled children (89.29%), there was quite a bit of variability with respect to the typically-abled child's degree of involvement in the care of the individual with an intellectual disability. This variability appeared to be associated with parental planning behaviour – in particular, having largely uninvolved typically-abled children appeared to be associated with concrete planning, and having very involved typically-abled children appeared to be associated with informal planning.

Uninvolved/Distant Typically-Abled Children: Concrete Planning

Parents who had typically-abled children who were largely uninvolved in the day-to-day life of the individual with an intellectual disability frequently appeared motivated to develop concrete plans. In particular, parents often desired their typically-abled children to play some sort of role in the future of the individual with a disability; however, to off-set the limited knowledge that these uninvolved children likely had of the individual with a disability, some parents seemed to feel pulled to develop detailed, concrete plans. In this way, parents hoped that the detailed plans they were creating would serve as a useful guide for their children who were, perhaps, well intentioned, but largely unaware of the needs of the individual with an intellectual disability. This sense of creating concrete plans as a way of guiding more distantly involved typically-abled children is clearly evident in the statements made by one Concrete Planner as she reflected on why she and her husband had decided to develop concretized plans:

> ….By the time [the trust] is complete it will be quite specific…Because [his typically-abled siblings] are older than he is. He is adopted and he was adopted when the other kids were quite a bit older. I don't think they are as in tune with his needs as much as they could be. So I think for ease, for ongoing ease, we need to be specific about what he needs. **(**CP4)

Some parents who had typically-abled children who were largely uninvolved in the day-to-day life of the individual with an intellectual disability also appeared motivated to engage in concrete future planning as a way of limiting the typically-abled child's responsibilities with respect to the future care of the individual with an intellectual disability. These parents generally recognized the tremendous amount of work caring for the individual with a disability had been for them, and voiced a desire that their typically-abled children not face the same challenges. For example, one Concrete Planner, in talking about her motivation for developing concrete plans that were largely independent of intervention on the part of her typically-abled daughter, stated, **"**I didn't want my younger daughter to basically be saddled with the care of her sister. I knew how hard it was on me; why would I ever wish that on her?" (CP11). Similarly, another mother who had created concrete plans that required little input from her geographically-distant typically-abled daughter, explained:

> [Our typically-abled daughter's] an Alberta girl now. She'll never move back to the island. But in the back of her mind, she's probably thinking, "if I stay in Victoria, I will have to look after [my sister] for the rest of my life." And I didn't want that. I'm glad she went away. That's her independence. She wasn't brought into this world to have to look after her sister. But, god forbid, she has to make a major decision, she's there to do that. (CP12)

Involved Typically-Abled Children: Informal Planning

Having regularly involved, typically-abled children appeared to support informal planning. Parents of highly involved typically-abled children generally had a great deal of trust in their child's ability to effectively manage the care of the individual with an intellectual disability. This trust, in turn, appeared to encourage parents to create fairly informal future plans, as they were generally confident that their child would navigate future decision-making in a manner that best met the needs of the individual with an intellectual disability and that was consistent with the parents' core values. One Informal Planner very effectively illustrated this apparent connection between having a regularly involved, typically-abled child and the development of informal plans as she reflected on the reasons why she and her husband were comfortable creating largely informal plans:

> We're flexible because I trust my daughter completely. We've had good conversations about it. She's well aware that her responsibility is to take care of [our son's] needs once we're gone. And she's fine with that….Basically, her and I are so much alike. She knows me really well and I know her really well, so whatever she does I trust her…. She's not a typical big sister; she's more like a third parent. She would agree with that, I'm sure. (IP1)

Similarly, another mother who had developed informal plans which centered on the intervention of her typically-abled son and daughter echoed this sense of faith in her children's abilities to manage the care of her son with a disability, regardless of how the future might unfold:

> No matter what, I know that his brother and sister will be there to help him out, no matter what in the end. If something happened to my husband and I, we know that they would be there to help out…I have every faith in his brother and sister and their husbands and wives that they'll be there to help him out as needed. (IP10)

Parents who viewed typically-abled children as playing a primary role in future of the individual with an intellectual disability were also often sensitive to the potential of creating plans that were unnecessarily restrictive for their typically-abled children. As is evident in a following statements made by an Informal Planner who viewed her typically-daughter as playing a seminal role in the future, parents often wanted future plans to remain informal as a way of keeping their typically-abled children's roles and responsibilities for the future fairly flexible and adaptable to their changing life circumstances:

> I would like to keep [plans] open and flexible. Because, you know, I don't want to tie [my typically-abled daughter] into something that she doesn't want to do. So if something were to happen to us and she wasn't able, you know, then she's not able. (IP13)

Perceived Social Support

Limited Social Support: Concrete Planning

Having limited social support also appeared to be associated with concrete planning. In short, parents who reported having minimal extended family and minimal support from friends appeared motivated to create concrete future plans as they did not have the built-in assurance of knowing that others would naturally assume responsibility for the care of their child with an intellectual disability in the event of the parent's death or serious illness. This idea of being driven to plan concretely as a result of limited social support is clearly evident in the statements made by one mother as she explained her decision to develop very formalized future plans for her son:

> It's not like there's lots of brothers and sisters and aunts and uncles that can step in. Who care, know, are committed to [my son], and who could step in. [There's] just his sister, and…my conscience [is] not wanting just his sister to have to carry on and to be isolated with all the responsibility for [my son]… (CP7)

High Social Support: Informal Planning

Parents who reported having large extended families and broad social support networks generally felt confident that friends and family members would step in to fill the void left in the life of the individual with an intellectual disability in the event of the parent's death and/or serious illness. For example, one mother who had engaged in very informal planning still felt certain that her son with a disability would be well cared for in the post-parental care phase of his life due to her high degree of social support:

> I know that if something should happen to me tomorrow then [my son] would be well looked after by either his sister, or my friends on the farm, or any of my friends or social network. They would be more than happy to be taking over. (IP6)

With this in mind, parents with high social support often believed that informal plans, which provided an idea of what they would like for their child's future but which were flexible enough to respond to the inputs of a range interested parties, were well-suited to their needs.

3. Suggestions for Improving the Future Planning Process

The data analysis highlighted important ways in which the future planning process might be improved upon and/or better facilitated. Across Concrete Planners and Informal Planners, key ideas were identified regarding how the formal service system might be changed to better support parents in developing future plans. In addition, across groups, important themes relating to how parents, themselves, should approach and engage with the future planning process also emerged.

Proposed Changes to the Formal Service System for the Purpose of Improving the Future Planning Process

Prior to discussing how the formal service system might be improved to better meet the future planning needs of parents, it is important to note that several parents in this study voiced appreciation for the assistance and services offered to them by CLBC. In addition, many parents also recognized the difficulties faced by CLBC in trying to meet the diverse needs of the population they are mandated to service. For example, one father, in reflecting on the challenges he had encountered when trying to access services from CLBC, explained,

> CLBC is always going to have limited resources. It doesn't matter if you give them another 50, 100, 200, 300 million [dollars] -- demand is always going to outstroke supply. So they have a special challenge in terms of how to manage that system. (CP10)

With the above statement in mind, it is conceivable that the formal service system will always, to some degree, struggle to meet the needs of individuals with intellectual disabilities and their parents. The ideas discussed below, however, represent important suggestions from parents of individuals with intellectual disabilities regarding how the formal service system might be adjusted to better meet parents' future planning needs.

Streamline the System

In discussing challenges encountered when trying to move forward with developing future plans, many parents highlighted the need for the formal service system to be streamlined. In particular, as illustrated by the quotations below, several parents spoke to the need for the process of accessing services and supports to be simplified:

> It did take a while to hook into the system. You have to fill out many, many forms and then, of course, it went from the Ministry to CLBC, so you had to do it all over again....We had to repeat everything. It's almost like they didn't pass on files. You started from scratch all over again. Different social worker, different everything, you had to just start all over again. And I'm sure that was very frustrating for a lot of parents. (CP9)

> I'm not asking for more money, I'm asking for less administration. And certainly that 23-page application form [for accessing Disability Assistance] is beyond ridiculous when I have a psychologist's report and a doctor's letter. That 23 page thing, the waste of my doctor's time to complete that....It's just a total waste. (IP9)

Parents in this study also felt that the roles and responsibilities of CLBC personnel need to be clarified, highlighting how difficult and frustrating it can be to move forward with developing future plans when so much time must be spent trying to figure out layers of bureaucracy.

> It's a better system here, but much more complicating and, as parents, you just get totally burned out trying to figure this out. (CP10)

> ...[The system's] inherently confusing. Absolutely confusing. And it's emotionally charged. It's just overwhelming trying to figure out who all the people are and what role they really might play. (CP15)

Provide more Guidance with respect to Future Planning

Many parents in this study felt that the formal service system should take a much more active role in supporting and assisting parents in developing future plans for their children with intellectual disabilities. As illustrated by the following quotation, some parents yearned for clear guidelines around which they could develop their plans:

> I wish there was a plan that could be put in place so all families could have a model that worked so they didn't have that fear and concern about their child's future. (CP8)

Other parents spoke to a desire for more active and early encouragement from the formal service to develop future plans. These parents felt that the service system needs to place more emphasis on encouraging parents to begin the future planning process when their children are young. In addition, they felt that the formal service system should make efforts to periodically revisit the issue of future planning with parents throughout their children's adulthood. One father, who was very engaged with CLBC, spoke to this need,

> …One thing I've emphasized with my connections within the Ministry and CLBC is that planning really has to begin early, like 14-years-old, I would recommend. I think that there has to be some support for that from all the stakeholders – so that would be the education system, the health care system, parents need to be involved. And I think that active planning and just saying, "hey, you need a plan" is really important…So I think that's something where help has to be available from somewhere in the social service system - to facilitate that. (CP2)

Move Away from Crisis-Response Orientation

Parents in this study overwhelming felt that the formal service system was primarily crisis-oriented. In this way, and as illustrated by the statements below, many parents believed that a horrible event (i.e., illness, injury, death) would have to transpire in their lives and the lives of their children with disabilities before the formal service system would take meaningful action:

> …It took a hell of a threat to CLBC. We had gotten to the point where we threatened to bring [our daughter] down and just drop her off at the office and say, "it's your problem." And it honestly was a reflection of the crisis situation we were in, and we could not cope any more. (CP10)

> Once that [transition] plan is written and the present needs are dealt with, they [CLBC] step out. I haven't heard anything from them for almost two

> years now…So unless I went to them and said, you know, "I've just got an injury and I can't take care of my son," they're not going to be involved at all…They only step in if one or both parents die. (IP1)
>
> …You would like to think that in Canada…[the government] would care about people. That they would care that you don't have to get to a crisis mode…where one of us passes away or medically we can't take care of [our daughter] anymore. But it's not happening and that's our frustration. (CP3)

With these statements in mind, parents in this study felt that the service system needs to shift from a crisis-response orientation and, instead, adopt a more proactive stance, where attention is being focused on helping parents prepare for the post-parental phase of their children's lives – including both providing guidance with respect to future planning (see above point), and also increasing the availability of formal services upon which future plans often rely (i.e., housing, funding). As noted by one parent, this increased focus on preparation for the post-parental care phase should help to decrease the likelihood of a crisis occurring in the event of a parent's injury, illness, or death; and, moreover, would likely be less costly to the service system in the long term:

> …If you look at CLBC, one of the largest chunks of their budget goes to crisis intervention. And why the crisis's happen, well not always, but most of the time because there's no planning and supports in place. And why is there no supports or planning in place? Because nobody's planned. (CP2)

Expand Housing Options

In reflecting on potential housing options for her daughter, one concerned mother stated, "having done some research, there's not a whole lot out there to choose from. So I guess it is the idea of not having a lot of options that is kind of scary" (IP3). Bearing this statement in mind, it is perhaps not surprising that, due to a perceived lack of desirable housing options for adults with intellectual disabilities, many parents in this study indicated finding it challenging to move forward with developing future plans. Parents voiced a range of concerns about currently funded housing models (i.e., group homes, home shares). The following quotations represent a sampling of the concerns raised by parents regarding available housing options:

> …We looked at this home share thing….And we rejected it absolutely…The problem with home share is that it's only as long as that person running it wants to do it. (CP10)

> …We looked at the home share option and I realized just how badly managed that was. Putting children into very unsafe situations where they weren't getting the care that they needed… I've met with people who had to take their kids out of home shares because they were neglected or not getting the care they needed. So that's not an option I would want to consider. (IP1)

> …There's only so much staffing in a group home and there's only so many things they can do…I know that if somebody lives in a group home there may only be a few outings per week because they have to split among everybody, and it's usually with other people….The interests of the people that live in group homes may not be the same interests of [my son]. I don't believe he would be happy in that situation. (IP10)

> We went into this [group home] and it just broke my heart. It was just an absolute shit hole…Like the bedroom that [my daughter] was going to be in had no blinds on the window. There were a couple of holes in the wall. There were no doors on the cupboards. It needed painting; it was all scraped up. The bathroom - the tub was all rusty, the toilet was rusty, the sink was rusty. There was mold in the bathroom. (CP12)

Given these concerns, many parents highlighted the need for expanded housing options – particularly expanded independent living and shared living housing opportunities - when developing plans for their children with intellectual disabilities. As illustrated by the following quotation, parents in this study frequently spoke very passionately to this need:

> If you foster integration and then when [people with intellectual disabilities] are 20, you say, “”all you can do now is move into someone's basement,” then

> that experiment has failed in its entirety because all the work you've done adds up to nothing. We did all that work of having all the intervention and all the child development and the school being integrated. It should culminate in some kind of shared living situation….It's almost like that last piece isn't there yet. (IP7)

> …We went from institutions to group homes and now home shares and I think the next wave will be more independent living for people with developmental disabilities. That's what they're wanting, and there's a big push on their part to get it. And they've lived in community. That's what they want. That's what we all wanted. We could hardly wait to get out on our own. (CP9)

Another participant in this study also highlighted the potential utility of developing housing complexes designed to meet the needs of both the aging parent and the aging individual with an intellectual disability. As this parent noted, such a facility would help to foster and maintain the strong bond that frequently exists between parents and their children with intellectual disabilities, while also ensuring that individuals – whether they be the aging parent or the individual with an intellectual disability – are receiving an appropriate level of care.

Improve Transition from Child Services to Adult Services

Many parents in this study felt that future planning should begin early in the lives of individuals with intellectual disabilities; however, they also felt that their intentions to begin the planning process early were sometimes hindered by their child's abrupt transition from child and youth services to adult services at the age of 19 years. As illustrated by the statements made by one frustrated parent, this sudden transition to adult services can pose numerous challenges to parents and their children with intellectual disabilities:

> At the same time you are transitioning, you are also losing all your support system. You lose your social worker that you've bonded with over the years. You lose after school programs. You lose autism funding. You lose your

> respite services. Everything stops at the same time that they're transitioning into adulthood. So you're also in a complete state of chaos over the loss of all your supports. So it's double whammy…It took my son at least a year and a half to adjust to adult services and he still has bad days. (IP1)

As is evident in the above quotation, transitioning to adult services generally represents a time of marked and sudden upheaval in the lives of individuals with intellectual disabilities and their parents. Perhaps understandably, such global changes can effectively stall the future planning process, as valuable time and energy must be spent on becoming acquainted with the new service system, and on reestablishing services and supports for the individual with a disability.

With these challenges in mind, several parents highlighted the need for the transition from child- to adult services to become more of a graduated process, in which child services are gradually replaced with their adult counterparts over a designated period of time. As reflected in the statements made by two mothers, parents also spoke to the need for CLBC to begin working with parents and children with intellectual disabilities well in advance of the child's nineteenth birthday as a way of ensuring needed services and supports are in place at the time the transition to adult services occurs; which, in turn, would enable parents to have a better sense of what theirs and their child's lives will look like moving forward.

> I tried to start at 17, but then [CLBC] said it was too early. And then they said, "oh no, we can't start providing services until she's 19. And we can't even start to look for services until she's 19." And you know, all this sort of crap…I said "that's ridiculous. How do you expect families to function when there's no transition?" There's no nothing. So it probably wasn't until about a month before she was 19 that we finally had things in place. And that's very difficult for me. (CP14)

> [My son] had one and a half days of school left when I found out whether or not he would get funding for a day program….We didn't know if we were

> going to have to sell our house, or if I was going to have to quit my job, or what we were going to do if we didn't get that funding. (IP1)

By developing a smoother process of transition from child services to adult services, it is possible that parents who wish to begin future planning early in their children's lives would be less likely to have their planning interrupted by this period of transition. In addition, it is possible that efforts to improve the transition from child- to adult service might encourage parents who do not currently feel that early future planning is feasible to view it as being more of a possibility.

Strive for Greater Stability within the Service System

Several parents in this study highlighted the challenges of moving forward with developing future plans – particularly plans that rely on the formal service system - in the face of uncertainty regarding long-term availability of funding and supports for individuals with intellectual disabilities:

> …You can think, "well this is what I want and this is what's going to happen," and then it's not going to happen. Things change…I mean who's to say in 20 years what it will look like in the government? They may not even provide funding anymore. I mean who knows? You just don't know. (CP12)

> ….The group home arrangement should be forever, [but] who knows what can happen down the road. [We] might have some completely right wing government elected who says, "no, they all have to leave." …. So, you know, a lot of things can change as the decades roll by. (CP10)

> Hopefully there's not changes to funding, but you never know. I mean, they just two years ago went through drastic cuts. You know, you're sort of at their mercy. (CP14)

With these concerns in mind, parents voiced a desire for a greater degree of consistency and stability with the formal service system. While parents generally recognized that that the formal service system will naturally change over time (e.g., "I think that…CLBC is subject to changes given the government budget, and it's also subject to change in how the world itself changes" (IP7)), many parents in this study still voiced a desire for some level of commitment or guarantee that the supports and funding upon which they and their children with disabilities relied would continue to be available in the post-parental care phase of their children's lives.

> I wish that I knew for sure that [my son] would be living and growing old [in the home share] where he has moved and where he is now. And I don't know that. That's what we can intend and plan for….I hold hope…And I continue to dream for my son. (CP7)

Advice for Parents when Developing Future Plans

In addition to identifying important ways that the formal service system might be changed to better support parents in developing future plans, parents in this study also provided key suggestions for how parents, themselves, can improve upon future planning for their children with intellectual disabilities.

Keep the Needs and Preferences of the Individual with an Intellectual Disability Forefront when Planning

Many parents in this study highlighted the need for parents to ensure that the future plans they are creating are well-suited to the needs and preferences of the individual with an intellectual disability. With this in mind, several parents stressed the importance of actively involving the adult child with a disability in the creation of future plans, and the importance of really listening to and considering their child's wishes in the development of plans. As noted by one parent, this decision to involve children in the planning process is, unfortunately, not the reality of how many parents choose to approach future planning:

> I see this so much, parents do not listen to their children. They think they know what their children need. They just don't trust that their children

> know what they want. So they're busy planning with their children on the outskirts and that drives me crazy. You need to spend the time with your kids. (CP9)

Parents in this study also spoke to the need for parents to be mindful of creating future plans that are intended to fit the individual with a disability, as opposed to expecting the individual with a disability to fit the future plans. This point is best illustrated by the statements made by one mother as she reflected on what she perceived to be the growing popularity of social network planning:

> I guess I just want to say of course social networks are great. But always, always, always you have to come back to what's best for your child. And I guess that's the point - that we have to be really careful that we start with where the person's at; that we deal with what's at hand. (CP13)

Become a Strong Advocate

Several parents emphasized the utility of developing strong advocacy skills when formulating future plans for individuals with intellectual disabilities, particularly when plans rely heavily on the formal service system. As explained by one parent, “If [parents] don't have the wherewithal to do the advocating, I think you're just going to get lost in the system, unfortunately” (CP14). With this statement in mind, it is perhaps understandable that a number of parents in this study stressed the importance of parents being willing to advocate for the needs of their children with disabilities when developing future plans. This sense of needing to adopt a strong advocacy role in order to ensure that individuals with disabilities are receiving what they need both in the present and in the post-parental care phase of their lives is very evident in the statements made by two very impassioned parent:

> My gravestone is going to say "the bitch" on it. "Born 1951, died whatever." But you know what, that's your baby, that's your child. Of course you're going to fight for your child. (CP12)

> My life revolves around [my daughter]. I love her…Even though she's a lot of work and she screams at me most of the time, you know she deserves the best. I'll keep fighting. As long as I can. (CP14)

Allow Sufficient Time for Plans to Develop

Parents in this study also spoke to the need for parents to allow ample time for future plans to develop. In particular, a number of parents viewed planning as a slowly evolving process that, ideally, should not be rushed through. One parent, for example, in reflecting back on her and her husband's future planning process, explained:

> …It's been a gradual evolution of where we're heading…It's very difficult to think…of ourselves not being able to look after our disabled daughter….But then [our planning's] just evolved, knowing that that's something that we want to happen. We want her to be settled and happy before it becomes a crisis. (CP5)

This sense of plans evolving over time is also very evident in the statements made by another mother as she explained how, over time, parents must shift from "dreaming" plans to enacting plans:

> Let's put it this way; it's great to have a vision or a dream. But if you don't put practical plans of action in place, they only remain a dream….It will only stay a nice idea. So, I think you have to have the dreaming part, but then you say, "but what does that take?" Then you start to do that - you start to build that. (CP1)

Even after significant time has been dedicated to developing a clear vision for the future of the individual with an intellectual disability, several parents highlighted the extended time periods frequently needed to then formalize or enact plans. One parent, for example, in talking about formalizing plans for her son with a disability, explained:

> You can only do so much at a time. We started the legal piece for [our son's] …townhouse over two years ago. But it took us a year to put that in place - to get the funding and all those kinds of things. And then once we got that in place, then we had to do the legal piece to make the trust, and then do the legal piece to put the townhouse in his trust. Now that we've done all that, we now have to put all that into our wills. That's why I say you can only do so much. Legal stuff is very slow, it doesn't happen overnight. (CP4)

Become Knowledgeable about the Formal Service System

Many parents in this study spoke to the challenges of developing future plans when struggling to make sense of the formal service system. With this in mind, a consistent theme throughout interviews with parents was the utility of becoming knowledgeable about the formal service system when developing future plans, particularly with respect to learning about how services and supports are accessed. Specifically, parents in this study generally recognized that publically funded services and supports are limited resources. As a result, a number of parents stressed the importance of learning about how these resources are accessed and allocated. This challenge is clearly reflected in the statements made by one father as he explained his and his wife's approach to gaining access to a group home placement for their daughter with a disability:

> What we had to do is learn very quickly how the CLBC rating system worked and make sure that, you know, we scored as highly as possible to get what we wanted… Unfortunately, [gaining access to services] does come down to a battle, or the pitching, or presentation of the needs of the parent in the most appropriate format to the supplier of those needs, which is CLBC. (CP10)

This idea of learning how services are allocated as a way of ensuring access to needed supports is also very evident in the statements made by one mother as she explained the steps she used to take to make sure that her daughter continued to qualify for a particular service:

> …Every year your kid had to be re-evaluated to make sure they meet the criteria for the [program's name]. And all of us moms used to sit around and [joke], "god forbid our kid ever learned to walk or wipe their own ass, because they'd be off the program." [We] used to keep [our children with disabilities] up all night long…so when they met with the social worker, they couldn't do anything. The kids would be falling asleep…I mean how cruel is that? I remember once [the social worker] saying, "is she spoon feeding herself now?" And I go, "yeah!" She was, like, six years old and starting to feed herself. We're all excited, and they're going, "well she may not qualify now for the program…" (CP12)

Place Emphasis on Developing Strong Relationships

Parents in this study overwhelmingly stressed the importance of developing and fostering strong relationships between individuals with intellectual disabilities and the broader community. As illustrated by the following quotations, a primary reason for this emphasis was that parents felt that strong relationships are a powerful way of safeguarding an individual's future:

> We need to get [our daughter] connected with the community. The better known she is, and the more recognizable she is in her community, the more of a safety net can be shaped underneath her. (CP11)

> …The safeguard for [my daughter] mostly is just having people involved in her life. For her to have a community, and a community that is not ours, but her own – so, her caregivers and the professional people involved, and her friends at PLAN, the social community or whatever, and the microboard. (IP5)

In addition to safeguarding the individual with an intellectual disability, parents in this study also felt that relationships are very important from the standpoint of helping to ensure that, as much as possible, a parent's vision for their child's future is carried forward:

> We’ve been working on…creating this community of people that will want to continue her life, the life that she has, and the lifestyle that she's got, even when we can't do that anymore. (CP1)

Given the perceived importance of strong relationships in the lives of individuals with intellectual disabilities, parents spoke strongly to the need for parents to incorporate a range of people, representing a variety of relationships, into future plans. As one mother expressed, “…family members, siblings, anyone who is in a [your child’s] life and feels a commitment - a depth of desire to carry responsibility - I think needs to be circled [in]” (CP7).

Involve Others in the Planning Process

In addition to incorporating close others into future plans, many parents also emphasized the importance of involving close others in the creation of future plans. As explained by one parent, “I think what has helped me the most is to have processes where we plan inviting a lot of people into a planning process” (CP7). Many parents identified how involving other people in the planning process, whether formally (e.g., a microboard) or informally (e.g. family discussions), can help to strengthen planning by gaining a greater variety of perspectives on what represents the best interests of the individual with an intellectual disability. This value in a variety of perspectives is clearly evident in the statements made by several of the parents in this study:

> ….[When] you've got a larger group with everybody with unique gifting…I think you are able to come up things with a much broader scope, and also able to share that load. So I think that's better than just somebody leading. I know for me that I'm quite capable of leading and plotting out a path for [my son], but it's not the only way. (IP12)

> …You're inviting people to be part of understanding what your vision is…You're inviting creativity and ideas and connections from others. And

> some people who are there may say, “these are parts of something I will do - will commit to.” (CP7)
>
> I realized that…there needed to be more input from outside sources into how things were going to go for [my daughter]. There's way more ideas and way more support for both of us - especially for her. Then it's not just her mother making decisions. (IP5)

As is evident in the above quotations, many parents felt that involving close others in the development phase of future planning was also important from the perspective of gaining support for future plans and, thus, increasing the likelihood that close others will work to carry out the specified plans in the future.

CHAPTER 5: DISCUSSION

Introduction

The importance of parents planning for the futures of their adult children with intellectual disabilities has been increasingly emphasized in the literature in recent years (Heller, 2000; Heller & Caldwell, 2006). Current research clearly supports the benefits on multiple levels of parents engaging in the future planning process. For example, the development of future plans have been associated with benefits for the individual with an intellectual disability (e.g., less trauma associated with loss of parent), the parental caregiver(s) (e.g., decreased anxiety related to their child's future care), and the formal service system (e.g., fewer emergency services utilized in the event of the death of the parent) (Botsford & Rule, 2004; Gilbert et al., 2007; Heller, 2000; Heller & Factor, 1988; Kaufman et al., 1991). While it is now widely understood that developing future plans for the post-parental care phase of the lives of individuals with intellectual disabilities is important, there is still much to be learned with respect to how parents actually approach developing future plans. With this in mind, this thesis focused on the future planning of parents of adults with intellectual disabilities in a Canadian context. This chapter synthesizes the findings from this project in relation to the overarching research questions that guided this inquiry. Recommendations for future research, and for policy and practice, are also presented. Finally, this chapter closes with a reflection on the strengths and limitations of this study.

Synthesis of Research Findings

In this descriptive, exploratory study, the researcher sought to gain a richer understanding of parental caregiver's experiences with future planning for their adult children with intellectual disabilities. The overarching research questions guiding this inquiry were:

- How do parents plan for the future of their adult children with intellectual disabilities?
- Why do parents develop future plans for their adult children with intellectual disabilities in a given manner?

Through their participation in this research, participants provided detailed descriptions of their future plans, and reflected on the factors that they felt had influenced the form that their future plans had taken. In the following section, the key findings in relation to each of the above research questions are presented and synthesized with the existing research literature.

Findings Related to How Parents Plan for the Future

Rates of Planning

Traditionally, research that has focused on parental future planning for adults with intellectual disabilities has found that between one third and one half of parents have engaged in future planning (Bowey & McGlaughlin, 2007; Freedman et al, 1997; Heller & Factor, 1991; Kaufman et al., 1991; Krauss & Seltzer, 1995; Prosser, 1997). Within this body of research, however, future planning has almost always been defined as relating to concrete planning behaviours – most prominently, concrete residential planning (i.e. placing the offspring's name on a waiting list for a residential placement, transitioning the individual with an intellectual disability out of the parental home) (Bigby, 1996, 2000).

The only study (i.e. Bigby, 1996) that was identified that explored rates of planning using a more inclusive definition of future planning (i.e., any ideas or arrangements made by parents that concerned the care of their adult child with an intellectual disability in the post-parental care phase of their life) yielded dramatically different results, as compared to studies that utilized a traditional definition of future planning. Specifically, Bigby (1996) found that 95% of participants had engaged in some form of future planning. Importantly, the current research project, which utilized Bigby's (1996) definition of future planning, found comparably high rates of planning. In fact, within this study, all participants were identified as having engaged in some form of future planning for their adult children with intellectual disabilities.

The very high rates of planning observed in this research, and in Bigby (1996), highlight the fact that future planning is a multifaceted process, which extends beyond a few specific planning actions or tasks. By adopting an overly narrowed definition of future planning, the risk is that other planning behaviours, which fall outside this definition (e.g. brainstorming with loved ones, informally designating someone to act as an advocate in the future, building relationships, etc.), may be overlooked and devalued. Moreover, such a circumscribed definition of future planning also assumes that all parents should be planning in a similar way for their adult children with disabilities. Based on the findings of this research, this assumption grossly oversimplifies how parents appear to be engaging with the future planning process in real life practice.

To gain a more nuanced understanding of parental future planning, this study sought to examine the forms that participants' future plans took in relation to three previously identified future planning approaches – namely, concretized planning, key person succession planning, and social network planning. With respect to concretized planning -- which has been the approach to planning for which most researchers and professionals have advocated (Bigby, 2000; Heller & Factor, 1991; Smith et al., 1995) -- 26/28 participants had engaged in some form of concrete financial planning; 19/28 had engaged in concrete planning relating to guardianship or other less restrictive alternatives, and 15/28 had engaged in some form of concrete planning regarding future housing needs. Overall, the rates of concrete planning in relation to finances, guardianship, and housing that were observed in this study are somewhat consistent with past findings. Specifically, past research has found that approximately half of all parents have engaged in concrete residential planning (Freedman et al., 1997; Joffres 2002; Kaufman et al., 1991); which is in line with this study's finding of approximately 53% of parents having developed concrete plans with respect their children's future housing needs. Further in line with past research is the finding that significantly more parents engaged in concrete financial planning as compared to concrete residential planning. For example, Kaufman et al. (1991) found that slightly less than half of the parents in their study had engaged in concrete residential planning, whereas two-thirds of these parents had developed concrete financial plans.

The rates of concrete financial planning observed within this study are significantly higher than has been found in past research. One possible explanation for this high rate of concrete financial planning is the fairly recent development of the Registered Disability Savings Plan (RDSP); which first became available in 2008. In brief, the RDSP is a Canada-wide, matched, tax-deferred savings plans designed for people with disabilities (Etmanski, 2009). For every dollar that is contributed to an individual's RDSP, the federal government will contribute up to three dollars, depending on household income (Etmanski, 2009). The amount of money in an RDSP does not impact an individual's disability income and related benefits (Etmanski, 2009). The British Columbian Government was the first provincial government to enable families to make full use of the RDSP, and the Crown Agency responsible for supports and services (i.e. CLBC) has played an active role in encouraging parents to set up RDSPs for their offspring with intellectual disabilities. With this in mind, it is perhaps not surprising that the vast majority of parents who took part in this research had set up an RDSP. Moreover, several parents, in the absence of most other forms of concrete planning, had still set up an RDSP. Overwhelmingly, parents were enthusiastic about this initiative, and felt that it represented an important step toward securing their loved ones' financial futures.

Turning to the less well-established future planning approaches of key person succession planning and social network planning, approximately 78% (22/28) and 64% (18/28) of parents in this study were found to be using these two approaches, respectively. Importantly, the finding that 78% of parents were using some form of key person succession planning is largely consistent with the findings of Bigby (1996) that 75% of parents in their study made use of this approach, frequently in conjunction with other forms of planning.

In keeping with Bigby's observations regarding the possibility of different forms of key person succession planning, within this study key person succession plans were found to range from being well-elaborated and highly prescribed (what Bigby refers to as "explicit key person succession plan") to those that appeared much more vague and informal (described as "implicit key person succession plans" by Bigby). The "key people" within participants' plans were most often typically-abled offspring, which is largely in line with recent research that suggests that many parents view their typically-abled offspring as playing key roles in the future plans they develop for their children with intellectual disabilities (Davys, Mitchell, & Haigh, 2010; Dew, Llewellyn, & Balandin, 2004; Heller & Arnold, 2010). With this in mind, it is perhaps not surprising that, as of late, significant research efforts have been focused on trying to develop a better understanding of how these "sibling carers" navigate and manage their new caregiving roles and responsibilities (Bigby, 1997; Dew et al., 2004; Ormond & Seltzer, 2000).

With respect to social network planning, no previous studies were identified that actually document the frequency with which this approach has been utilized by parents as they develop future plans. With this in mind, the finding that almost two-thirds of the participants were utilizing some form of social network planning represents an important contribution to the literature on future planning. This relatively high rate of social network planning underscores the growing recognition of the importance of building strong relationships when attempting to safeguard the future of an individual with an intellectual disability (Etmanski, 2009).

Importantly, within the context of British Columbia, the belief that relationships are an integral part of developing future plans appears to be increasingly accepted. Social network development is currently actively promoted by CLBC (CLBC, 2009), and there are several British Columbia-based agencies that facilitate social network development and maintenance (e.g, Lifetime Networks, Planned Lifetime Advocacy Networks (PLAN), Vela Microboards) – sometimes for a fee. Interestingly, while the majority of parents highlighted the importance of building and maintaining strong social ties in their future plans, only the minority of parents indicated that they were willing to pay for formal services designed to promote social network development (i.e., PLAN); many felt that they could perform the same function themselves without incurring the additional cost. Given the growing interest in social network planning – in conjunction with the proliferation of services designed to facilitate such planning -- future research should explore whether social networks designed and maintained by fee-for-service agencies are more successful in meeting the needs of individuals with intellectual disabilities in the post-parental care phase of their lives, as compared to social networks that are not overseen by such agencies.

Variability in Future Planning

Overwhelmingly, the parents who took part in this study were drawing on more than one future planning approach when developing future plans for their adult children with intellectual disabilities. This finding of overlap in planning approaches is in keeping with suggestions made by Bigby (2000). Specifically, Bigby suggests that certain approaches may be used in tandem because of their complementary functions. For example, Bigby highlighted the potential for key person succession planning and social network planning to be used together. She explained that parents may choose to bring together a group of people to share in decision-making and to work together to support the individual with a disability, but that these parents may also choose to elect one "key person" to have the final say on matters relating to the target individual. This scenario was clearly evident in the future plans of several of the parents who participated in this research -- parents often reported that they felt a number of family members and friends would be involved in supporting their adult children in the future, but they also usually felt that there was one particular person -- most usually a typically-abled offspring -- who would be the final decision-maker and main contact person for service providers.

Bigby (2000) also notes the potential for overlap between concretized planning and key person succession planning, in that parents may develop well-elaborated concrete plans which they then designate a "key person" to carry out. Bigby suggests that key person succession plans within this context may be quite formal, with the designated key person having a clearly articulated set of tasks and responsibilities that they are expected to perform in the post-parental care phase. Again, this relationship between the planning approaches of concretized planning and key person succession planning was evident in the future plans of a number of the parents who participated in this research.

Parents in this study varied not only in terms of the combination of planning approaches they used, but also in terms of how they chose to implement individual planning strategies. As a result, even parents who were found to be using the same combination of planning approaches often had future plans that looked markedly different. For example, while one parent might describe the social network component of their plans as being responsible for overseeing all major areas of their child's future, another parent might see the social network's role as being limited to responding to their child's social and recreational needs.

Overwhelmingly, the variability in the implementation of future planning approaches that was observed in this research suggest that a "one-size-fits-all" approach to planning is likely not appropriate for supporting parents in their attempts to develop future plans for their loved ones. Moreover, the observed overlap and variability in planning approaches may be viewed as one possible explanation for why future planning interventions (Botsford & Rule, 2004; Etmanski, 1997; Heller & Caldwell, 2006; Susa & Clark, 1996), which are most often focused on parents developing concretized plans in several key areas (i.e., finances, legal issues, housing), have often had fairly limited success in promoting the development of long term future plans**.** Ultimately, the marked variability that was observed in this research appears to underscores the need for "person-centered" and/or "family-centered" planning supports that are capable of responding to the unique constellation of factors that are associated with each particular caregiving situation (e.g., family circumstances, personal beliefs and values, care-recipients needs and preferences, etc.).

Conceptualized Groupings

Taken together, the findings from this research illustrate how complex the future planning process is, and how difficult it can be to distill the planning process down to a few key elements, or to describe future planning according to a few pre-defined planning approaches (i.e., concretized planning, key person succession planning, social network planning). Instead, findings suggest that parental future planning may be better conceptualized along a continuum ranging from parents who have developed plans that are very formalized and concrete, to parents who have plans that are largely informal in nature. Using this idea of a continuum of future planning, it was found that 15 parents in this study had plans that were predominantly concrete (i.e. Concrete Planners) and 13 parents had plans that were predominantly informal (i.e. Informal Planners).

Viewing parental future planning along a continuum appears to be useful for a number of reasons. Perhaps most obviously, such a perspective is valuable as it allows for consideration of the less formal planning in which many parents appear to engage. This is important as there is some research to suggests that informal planning may still be an effective form of future planning (Bigby, 1996). Such plans have been found to effectively facilitate transition from parental care, and to be an effective means of dealing with unexpected events in the post-parental care phase of the life of the individual with a disability (Bigby, 1996; Bigby, 2000; Bigby et al., 2011). With this in mind, it would seem that failing to consider informal plans as a legitimate form of future planning perhaps unfairly discredits the important work that many parents have put towards safeguarding their children's futures, albeit informally.

Understanding future planning behaviour along a continuum also encourages recognition of the fact that even parents who are predominantly Informal Planners may choose to formalize certain elements (e.g., finances, housing) of their future plans. Conversely, parents who emerge as being largely Concrete Planners may still feel that leaving certain areas of their child's future life more informally planned is preferable (e.g., social/recreational needs). In keeping with this viewpoint, no parents in this study emerged as being solely concrete or solely informal in their planning behaviour.

Finally, viewing future planning along a continuum also allows for consideration of the fact that many parents may be working towards further concretizing plans over time**.** In keeping with this hypothesis, several of the parents who were identified as Informal Planners explicitly noted that they had intentions of further concretizing plans in the future; and a number of the Concrete Planners spoke to the fact that their plans had become increasingly formalized over time. Importantly, this hypothesis appears to be in line with suggestions made by past researchers that stages of planning may vary across the life course (Essex et al., 1997; Hewitt et al., 2010; Joffres, 2002; Smith et al., 1995); and that planning is best understood as a process as opposed to a discrete event (Bowey & McGlaughlin, 2007).

Importantly, the recognition of there being a continuum toward increasingly formalized future plans could have important implications for formal services aimed as facilitating future planning. Specifically, services aimed at facilitating parental future planning might be more effective if attempts were made to tailor intervention strategies to the point along the continuum at which a particular parents falls. For example, parents who are predominantly engaged in informal planning might find strategies focused on more general information provision and relationship-building with service providers most useful. In contrast, parents who have moved towards developing increasingly concrete plans might be best served by workshops specifically focused on helping them perform discrete planning tasks (e.g. setting up a trust fund, establishing a representation agreement).

While the majority of parents who were identified as Informal Planners appeared to be aspiring towards increasingly formalized plans, there were a few Informal Planners who indicated that they did not intend to further formalize their plans. In this way, within the group of Informal Planners, there appeared to be two distinct subgroups – namely, “Transitional Informal Planners” (the much larger group) and “Stable Informal Planners.” Importantly, this finding is in line with suggestions made by past researchers that plans may sometimes remain at the informal level, never developing into the comprehensive, concrete plans for which researchers and service providers frequently advocate (Bigby, 1996, 2000, 2004; Bowey & McGlaughlin, 2007; Heller & Factor, 1991).

This finding of the possible existence of Stable Informal Planners versus Transitional Informal Planners highlights potential avenues for future research. Specifically, if possible, it would be interesting to re-interview these Informal Planners in several years to assess the degree to which plans have changed over time. Such research would provide a clearer understanding regarding whether parents who identify as “Transitional Informal Planners” actually do move toward increasingly formalized plans over time. Such a focus would also help to establish whether parents who identify a preference for keeping plans fairly informal actually maintain this conviction over time. In the event that a distinct group of Stable Informal Planners is found to exist in follow-up research, it would be important to explore the outcomes associated with their informal future plans versus the outcomes associated with the more concrete plans of other parents. Such research could be seen as building on the work of Bigby (1996), which was the only identified study that actually assessed outcomes associated with informal planning. Ultimately, such research could provide important indications regarding whether formalized future plans should always be encouraged or whether informal future planning also acts as an effective means of safeguarding the individual with an intellectual disability in the post-parental care phase of their life.

Findings Related to Why Parents Plan in a Given Manner

Beyond attempting to gain a better understanding of *how* parents plan for the futures of their adult children with intellectual disabilities, this research also sought to understand *why* parents plan in a particular manner. In comparing the characteristics of Concrete Planners and Informal Planners, seven factors were identified that appeared to distinguish between these two future planning groups.

The findings from this study regarding factors that appear to be associated with concrete planning add to an existing – although somewhat dated -- body of research. Importantly, some of these findings are in line with past research. For example, similar to the findings of Heller and Factor (1991, 1993) and Smith et al. (1995), this research revealed that greater involvement with the formal service system appeared to be associated with concrete planning. Further in keeping with the findings of past researchers (Grant, 1989; Kaufman et al., 1991; Heller & Factor, 1991; Seltzer et al., 1991), this study also found that higher income appeared to be associated with concrete planning. Finally, this study's finding that increased parental age appeared to be associated with concrete planning is also consistent with the findings of other researchers (Black et al., 1985; Heller & Factor, 1988; Sherman, 1988).

Interestingly, the finding in this study that higher degree of impairment in the individual with an intellectual disability was associated with concrete planning conflicts with past research. For example, both Freedman et al. (1997) and Kaufman et al. (1991) reported that parents of adult children with more severe intellectual impairments were less likely to engage in concrete planning, particularly with respect to their child's future residential needs. The reason for this discrepancy in findings is unclear. It is possible, though, that since the work of Freedman et al. and Kaufman et al., formal services have changed to the extent that parents now feel there are more appropriate services available for their adult children with high degrees of impairment; thereby, potentially making the task of developing future plans for individuals with high needs more manageable.

Another finding of this study that conflicts with past research is the suggestion that being married is associated with concrete planning. Specifically, Freedman et al. (1997) found the reverse of this, reporting that families in which the maternal caregiver was either divorced or widowed were more likely to have concrete future residential plans. Again, it is difficult to explain the reason for this difference in findings. A number of the married Concrete Planners within the present study clearly spoke to the value of having a partner with whom to share future planning responsibilities. Moreover, several of the single Informal Planners explicitly highlighted the challenges of planning without the assistance and reflective feedback of a spouse. It is worth noting that no other studies were identified that confirmed Freedman et al.'s finding, despite the fact that subsequent studies have also explored the association between marital status and planning behaviour.

As previously noted, the vast majority of research that has focused on future planning has traditionally defined planning in terms of concrete planning behaviours; therefore, to date, very little is known about the factors associated with developing informal future plans. The only study that was identified that sought to identify factors associated with informal planning was Bigby (1996). With this in mind, the current research project provides important initial findings regarding factors that appear to be associated with more informal planning behaviour.

In keeping with Bigby (1996), this research found that a high degree of social support and closely involved family members was associated with informal planning. In addition, this research extends current understanding by also suggesting that low socioeconomic status, low degree of impairment in the individual with an intellectual disability, younger ages of the parent and the offspring with a disability, being divorced, and having limited involvement with and/or negative perceptions of the formal services may also be associated with parents engaging in more informal future planning.

It is important to note that the findings of this research are based on a relatively small sample of people, and must be viewed with some degree of caution. That said, however, the results of this study can be seen as highlighting potential avenues for facilitating future planning in a particular way. For example, the findings suggest that having a high degree of knowledge of the formal service system is associated with concrete planning. With this in mind, if policy makers and service providers desire for parents to develop well-elaborated, concretized plans, greater focus should be placed on trying to improve information provision to parents regarding available services and regarding how services can be accessed. Importantly, other researchers have also identified a lack of information about the formal service system as being a significant barrier to developing formal plans (Bowey & McGlaughlin, 2007; Taggart, Truesdale-Kennedy, Ryan, & McConkey, 2012).

Along a similar vein, the results of this study also suggest that having substantial contact with the formal service system may foster concrete planning. Therefore, to promote concrete planning, service providers should find ways of increasing the formal service system's contact with families. One way of doing this might be for service providers to focus on increasing parents' access to respite services; which, frequently represent parents' first experiences with formal residential services (Gilbert et al., 2007). Additionally, as suggested by Bowey and McGlaughlin (2005), service providers might also try to provide opportunities whereby adults with intellectual disabilities are able to try out alternative living arrangements as a way of exploring available residential options. Provided these experiences are largely positive, the findings of this research would suggest that these efforts could be an effective means of furthering parental concrete planning, particularly with respect to residential planning.

The results of the current project also suggest that parents who do not feel positively about the formal service system, and about the service providers with whom they have contact, will be less likely to develop concrete plans. Again, if the service system's ultimate goal is to move parents towards developing concrete plans for their adult children's futures, then service providers need to place priority on building positive relationships with parents and with their offspring who have intellectual disabilities. Importantly, mistrust of the formal service system and of the individuals working within this system has been one of the most consistently linked barriers to developing formalized future plans (Bibby, 2012; Bowey & McGlaughlin, 2007; Davys & Haigh, 2007; Gilbert et al., 2007; Joffres, 2002).

Finally, a number of Informal Planners indicated that they did not feel that current service offerings were well-suited to the low impairment levels of their adult children. This finding suggests yet another means by which policy makers and service providers might attempt to increase concrete planning behaviour. Specifically, to encourage a wider range of parents to develop formalized future plans, policy makers and service providers need to strive to develop and offer services that meet a broad range of impairment levels and care needs. This idea again speaks to the need for the formal service system to try, as much as possible, to customize services to their individual clients, rather than expecting clients to simply fit into the services currently being offered. Based on the findings of the current research project, it appears likely that many parents would move toward developing concrete plans if they had the comfort of knowing that the formal services around which they must plan (e.g. housing) were a good fit for their adult children with more mild forms of intellectual disability.

Ultimately, the findings from this research regarding why parents plan concretely or informally were obtained through qualitative methodology that utilized a relatively small sample, which was drawn from one geographic area (i.e. British Columbia). With this in mind, further research – ideally quantitative in nature – is needed to test these initial findings. Specifically, by drawing on a significantly larger sample of people recruited from a much broader geographic area (i.e. Canada-wide), it would be interesting to determine whether the differences that were identified in this research between Concrete Planners and Informal Planners still hold.

Suggestions for Facilitating Parental Future Planning

Changes to the Formal Service System

While not the primary focus of this research, the parents who took part in this study also provided important insights regarding how the service system might be improved to better facilitate the future planning process. These suggested improvements are largely consistent with findings from past research that has sought to gain a better understanding of how parents might be better supported in future planning. For example, a number of the parents in this study highlighted the need for the formal service system to be streamlined, which is a need that has been noted by past researchers (i.e. Gilbert et al., 2007; Heller, Caldwell, & Factor, 2007; Taggart et al., 2012). Such researchers have called for making information about available services more accessible (Taggart et al., 2012), and the need for unnecessary barriers to accessing formal services to be removed (Heller et al., 2007).

Parents also spoke to the need for service providers to provide greater guidance with planning. Again, this finding is in line with the findings of past researchers (Gilbert et al., 2007; Heller et al., 2007; Hogg & Lambe, 1998; Hole, Stainton, & Wilson, 2013; Taggart et al., 2012). For example, in a United Kingdom-based study that focused on the support needs of parental and sibling carers, Taggart et al. (2012) found that the feeling that there was a lack of one-to-one support and guidance when developing future plans was a dominant concern of carers. To address this lack of guidance when future planning, Hewitt et al. (2010) suggested that case managers and other service providers within the traditional service delivery system be provided with increased training on future planning. Additionally, Hewitt and colleagues suggested that "future planning specialists" be hired, whose sole mandate would be to work with families to develop appropriate, well-elaborated future plans for their loved ones with disabilities.

Similar to prior research, parents who participated in this study also identified a need for the service system to move away from a crisis-response orientation and, instead, to place greater emphasis on helping parents prepare for the post-parental care phase of their adult children's lives well in advance of this transition (Bowey & McGlaughlin, 2007; Gilbert et al. 2007; Hole et al., 2013; Taggart et al., 2012; Thompson & Wright, 2001). Both Bowey and McGlaughlin (2007) and Gilbert et al. (2007) highlight the drawbacks of a crisis-response orientation, noting the increased trauma that occurs for parents and their offspring with disabilities when parental care ends suddenly and without appropriate preparation for such a transition. Furthermore, as noted by Bowey and McGlaughlin, such a crisis-response orientation often removes the opportunity for individuals with intellectual disabilities to be involved in developing appropriate and appealing future plans.

Parents who participated in this study also called for expanded housing options for individuals with intellectual disabilities, which has been a frequent refrain throughout the research focused on parental future planning (Bowey & McGlauglin, 2005; Taggart et al., 2012; Weeks, Nilsson, Bryanton, & Kozma, 2009). In keeping with prior research, parents identified a need for more independent living and shared living housing opportunities (Bowey & McGlaughlin, 2005; Higgins & Mansell, 2009; Weeks et al, 2009). Additionally, one parent desired housing accommodations that would support both aging parents and their aging offspring with intellectual disabilities. Interestingly, this suggestion for dual-purpose accommodations was also raised in another Canadian-based study. Specifically, Weeks et al. (2009) reported that several parents in their study felt cooperative living residential care options, which met the needs of both aging parents and their adult children with disabilities, would be a desirable housing alternative. As Weeks et al. noted, such a residential service option would help to honour and maintain the strong bond that exists between many parents and their children with disabilities. However, others have raised concerns about such a housing strategy, noting the major investments that would be needed in both facilities and staffing in order to ensure that the needs of both populations were being adequately met (Bigby, Webber, Bowers, & McKenzie-Green, 2008).

In light of the parental discomfort with available housing options that was observed in this study, as well as in past studies, policy makers and service providers might also explore how they can support and fund other family members to maintain the person with an intellectual disability within the family home after the primary parental carer can no longer provider care (Taggart et al., 2012). As noted by Taggart et al., such a strategy would likely be much more cost effective than moving the individual with a disability into full-time residential care. Moreover, maintaining the individual in the family home would likely be seen as being the most preferable housing option for many parents (Barron et al., 2006; Bigby, 2004; Heller, Caldwell, & Factor, 2005).

Finally, parents also emphasized the need for greater stability within the service system. Again, this finding is largely consistent with past research (Bibby, 2012; Hole, et al., 2013; Walker & Magrill, 2002). As noted by Walker and Magrill (2002), when considering the many changes that have occurred over the last fifty years with respect to how individuals with intellectual disabilities are treated in North American society, it is perhaps not surprising that stability within the service system is a major concern for parents as they attempt to plan for their offspring's futures. The older parents who took part in this study – as well as those who took part in previous research – likely have had first-hand experience with the transient nature of the government's response to disability, and, thus, are all too aware of how rapidly services and supports can change. Within British Columbia, this sense of instability within the formal service system has perhaps been heightened further by the numerous budget cuts and "service redesigns" that have taken place within CLBC in recent years (Kines, 2010). Placed within this context, it is perhaps understandable that parents might question the value of attempting to create concrete plans that are intended to extend well into the future.

Advice to Parents Regarding Future Planning

In addition to providing suggestions for how the service system might be changed to better support parental future planning, the parents who participated in this research also provided a number of important pieces of advice for other parents who are trying to develop plans for their children with intellectual disabilities. Taken as a whole, the thoughtful and insightful suggestions offered by these parents underscore the invaluable knowledge that parents who are "on the ground" possess. In this way, these findings highlight the importance of including the voices of parents, and drawing on the wisdom they have gained through years of providing care to their loved ones with intellectual disabilities, when developing policy related to the intellectual disabilities community, and when considering changes to existing services and supports.

On a positive note, CLBC appears to making efforts to draw on the wealth of knowledge that parents of adults with intellectual disabilities possess. Specifically, for the primary purpose of promoting community inclusion, CLCB has established a province-wide network of thirteen Community Councils that are comprised of adults with disabilities, family members, service providers, and other interested citizens (CLBC, 2014). As a bridge between the Community Councils and CLBC management, the Provincial Advisory Committee, which is comprised of members who are drawn from each of the thirteen Community Councils, has been established. The Provincial Advisory Committee meets four times a year to share what Councils are doing, to discuss issues and challenges, and to recommend improvements to policy and practice for the CLBC Board of Directors; these meetings are always attended by members of the Quality and Service Committee of the CLBC Board (Community Council Members' Handbook, 2014).

While CLBC seems to be making attempts to include parental voices in their approach to working with adults with intellectual disabilities and their families, the results of this study suggest that, where possible, parents' roles in shaping policy and service provision should be expanded further. The greater inclusion of parents would likely have several benefits. Perhaps most obviously, such an approach would likely result in services and policy that more accurately reflect real-life concerns and challenges, thereby presumably increasing the effectiveness of such services. At the same time, developing services in response to parental feedback would likely help to increase parents sense of trust and comfort with the formal service system.

Recommendations

This qualitative research project revealed important information regarding how parents plan for the adult children with intellectual disabilities, and regarding the factors that may be associated with parents planning in particular ways. These findings represent a sizeable contribution to the body of literature related to parental future planning, particularly as they reveal how prominently informal planning frames in many parents' future plans, and they highlight potential avenues for better supporting parents in the future planning process. Taken as a whole, the findings from this research have important implications for both research and policy and practice. The following recommendations are presented in two parts – recommendations for future research, and recommendations for policy and practice.

Recommendations for Research

There is still much to be learned about parental future planning for adults with intellectual disabilities. The following recommendations represent important ideas for future inquiry that will deepen our shared understanding of the future planning process.

1. An important future extension of the current study will be to conduct a Canada-wide research project to explore whether the distinct groupings of parental future planners (i.e., Concrete Planner, Informal Planners) that were identified in this British Columbia-based study still hold across a larger and more diverse sample.

The findings from this research project provide important initial insights into possible differences in how parents plan for the future; however, it must be noted that this research utilized a fairly small, ethnically homogeneous sample, and was limited to the province of British Columbia. Across Canada, services and supports for individuals with intellectual disabilities and their families vary widely (Hole et al., 2013; Joffres, 2002). It would be interesting to explore the extent to which the conceptual groupings of “Concrete Planners” and “Informal Planners” are still applicable in the face of different service delivery systems.

2. In an attempt to capture true differences in parental approaches to future planning, a longitudinal study focused on parental future planning for adults with intellectual disabilities could be established.

A longitudinal study focused on parental future planning would be able to shed light on whether parents who are identified as being “Informal Planners” at a given point in time are simply early on in the planning process, and with time, will move toward developing increasingly concretized plans (i.e. “Transitional Informal Planners”), or whether some parents who are initially identified as being Informal Planners actually continue to maintain their plans in an informal manner over the course of many years (i.e., “Stable Informal Planners”). If a distinct subset of “Stable Informal Planners” emerged, it would also be important to explore whether there are distinguishing factors between these two subgroups of informal planners.

3. Research could focus on examining outcomes associated with informal plans, as compared to concrete plans.

Minimal research has attempted to assess the outcomes of informal plans (i.e., Bigby, 1996), despite widespread recognition that parental future planning may often remain at the informal level (Bigby, 1996, 2000; Bowey & McGlaughlin, 2007). Future research could explore whether concrete planning and informal planning differ with respect to rates of emergency residential placement for individuals with intellectual disabilities during the post-parental care phase of their lives. In addition, research could explore whether concrete planning and informal planning relate to differences in parental caregiver outcomes (e.g., emotional well-being, health status, quality of life), and care-recipient outcomes during the post-parental care phase (e.g., emotional well-being, quality of life, perception of disruption in life).

Such research seems particularly important since, traditionally, academics, policy makers, and service providers have generally advocated for a concretized approach to future planning (Botsford & Rule; 2004; Heller & Caldwell, 2006; Heller & Factor, 1991; Smith et al., 1995). Presumably, if future research does not identify significant differences between concrete plans and informal plans with respect to various outcome variables, this would suggest the need for greater openness to a broader spectrum of planning approaches. Alternatively, if differences in outcome measures are found to exist between concrete plans and informal plans, this would lend further support to the idea that there is an "optimal" approach to future planning – whether that be concrete planning or informal planning.

4. A larger-scale, British Columbia-based, quantitative study is needed to test the findings from this qualitative research regarding the factors that appear to distinguish between parents who plan concretely and parents who plan informally.

The current project provides exciting indications regarding why British Columbian parents may choose to plan for their adult children with intellectual disabilities in particular ways. These findings potentially highlight meaningful avenues for facilitating particular forms of future planning in parents. At this juncture, a larger-scale quantitative research project is needed to test the findings of this project.

5. Future research could explore typically-abled offspring’s understanding of what their roles in the future care of their siblings with intellectual disabilities are expected to be.

In keeping with previous research findings (Davys et al., 2010; Dew et al., 2004; Heller & Arnold, 2010; Heller et al., 2007), many of the parents who participated in this research viewed one or more of their typically-abled offspring as playing a key role in their future plans. With this in mind, future research could focus on exploring typically-abled children’s understanding of what their roles in the future care of their siblings with intellectual disabilities are expected to be, as compared to parental expectations. Through such research, it would be possible to explore whether parents and typically-abled offspring share a similar vision for the future care of the individual with an intellectual disability. This research is particularly needed in light of this study’s finding that many parents engage in fairly informal types of planning that do not necessarily include clear directives for successors.

6. Research could examine the extent to which parental wishes with respect to the care of their adult children with intellectual disabilities are carried out by their typically-abled offspring successors.

Despite the increasing frequency with which typically-abled offspring are acting as successors for their parents in the care of their siblings with intellectual disabilities (Davys et al., 2010; Dew et al., 2004; Heller et al., 2007), no research has sought to understand the extent to which parental wishes and expectations relating to the care of the individual with an intellectual disability are fulfilled. In the face of increasing numbers of sibling carers, it is important that attempts be made to address this gap in the research literature.

7. Future research could focus on developing a deeper understanding of the effectiveness of social network planning in the post-parental care phase.

In the past decade, there has been growing interest in social network planning (Etmanski, 2009; Hillman et al., 2012), and, based on the findings of the current research project, it seems that many parents are drawing on this approach when attempting to plan for this offspring's futures. Despite growing support for this approach, there is currently a lack of understanding regarding the effectiveness of these networks in supporting the individual with an intellectual disability in the post-parental care-phase – particularly over extended periods of time. Future research could explore how functional social networks are in the long-term with respect to meeting the needs of the individual with a disability. Research could also examine the factors that are associated successful social networks (i.e., networks that continue to work well together over extended periods of time) versus the factors that are associated with unsuccessful networks (i.e., networks marked by a high degree of conflict and/or inaction).

8. Research focused on the future planning behaviour of parents of adults with intellectual disabilities should place priority on recruiting participants who are not currently in receipt of, or known to, formal services.

Research suggests that a significant proportion of families of individuals with intellectual disabilities are currently unknown to the formal service system (Janicki et al. 1998). Despite this, the majority of research focused on adults with intellectual disabilities and their families utilizes samples in which the vast majority of participants are in receipt of formal services (Bigby & Balandin, 2004; Heller et al., 2007). Unfortunately, despite attempts to recruit participants who were not currently known to the formal service system, the current research study is no exception to this trend –the majority of participants in this study reported some level of formal service utilization. With this in mind, it is possible that the patterns of future planning observed in this study were influenced by the relatively high rate of contact between parents and the formal service system. Attempting to recruit from the "hidden population" of parental carers (Jokinen, 2008) will likely yield important insights regarding "true" rates of future planning and forms of future planning across the spectrum of families of adults with intellectual disabilities – ranging from heavy users of the formal service system to those who are entirely unknown to the formal service system.

Recommendations for Policy and Practice

The findings of this research project also have important implications for policy and practice related to supporting parental future planning for adults with intellectual disabilities. It is hoped that these recommendations might help to inform policy making at the governmental level, agency strategic planning, and front line practice.

1. Consider strategies for encouraging future planning that do not alienate parents by forcing an overly prescriptive approach to the planning process.

The findings from this research suggest that a "one size fits all" approach to future planning does not capture the diverse forms of future planning in which parents of adults with intellectual disabilities are currently engaging. With this in mind, policy makers and service providers need to espouse a facilitative approach to future planning that addresses common needs (e.g. setting up an RDSP), but is also able to respond to the unique needs, values, and preferences of individual families as they face the challenging task of creating plans for the future care of their loved one with an intellectual disability.

2. Adopt a developmental approach when working with parents to develop future plans for their adult children with intellectual disabilities.

In keeping with the findings from this research that suggest that many parents may be on a continuum in which they are moving towards increasingly formalized plans, it may be necessary for service providers to adopt a developmental approach when working with families on developing plans (Bowey & McGlaughlin, 2007; Essex et al., 1997; Hewitt et al, 2010; Joffres, 2002; Smith et al., 1995). In this way, it is recommended that those in a position of supporting parental future planning first consider the point in the process that a parent is currently at – which could be dependent on a range of factors (i.e., age, SES, social/family support, marital status, connectedness with the formal service system) – and then work to provide planning support that is suited to that particular point.

3. Encourage early engagement with the future planning process in parents of adults with intellectual disabilities.

The fact that a number of the parents in this study indicated that they had intentions of further formalizing their plans over a number of years illustrates the extended time periods that are frequently required to develop well-elaborated future plans. With this in mind, the service system needs to play an active role in encouraging parents to begin thinking about their adult child's future well in advance of when they envision transferring their primary care role to another person or group of people. This is a need that has been indentified by previous researchers. For example, Hewitt et al. (2010), suggests that, for maximum benefit, parents should be exposed to planning supports when their offspring with disabilities are still fairly young.

4. Foster opportunities for learning about, and engaging with, the formal service system.

The findings of this research project suggest that providing families with opportunities to learn about and engage with the formal service system could potentially encourage the development of formalized future plans. With this in mind, greater focus should be placed on trying to improve information provision to parents regarding available services and regarding how services can be accessed. In addition, service providers should find ways of increasing the formal service system's contact with families**.** One way of doing this might be to consider increasing access to such high-demand services as respite care and day programs (Gilbert et al., 2007). Ideally, increasing contact with the formal service system in these ways would increase parents' knowledge of, and comfort with, available services.

5. Offer services and supports that meet a broad range of impairment levels and care needs.

A number of parents described being in a position of needing to draw on formal services (e.g. housing) when developing future plans, yet not feeling that the available services were well-suited to the needs of their respective children with intellectual disabilities. This perceived mismatch between available services and the needs and abilities of the individual with a disability appeared to be a significant barrier to moving forward with developing future plans. With this in mind, it seems clear that policy makers and service providers should strive to develop and offer services that meet a broad range of impairment levels.

6. Continue to explore different models for meeting the housing needs of individuals with intellectual disabilities.

Residential planning has sometimes been argued to be at the heart of future planning for individuals with intellectual disabilities (Bigby, 2000). With this in mind, it is perhaps not surprising that the parents in this study clearly spoke to the need for expanded housing options for their adult children with disabilities. In keeping with this need, service providers should continue trying to develop and explore different models of residential care and housing for individuals with intellectual disabilities. At the same time, in recognition of varying impairments levels and personal preferences, the service system should also strive to offer a range of residential options to better meet the needs of the diverse population of adults with intellectual disabilities.

7. Examine ways to improve communication and understanding between parents of adults with intellectual disabilities and the formal services designed to support them.

Communication between parents and service providers needs to be improved. The findings from this research, as well as from a number of other studies (i.e., Bowey &

McGlaughlin, 2007; Joffres, 2002; Bigby & Ozane, 2001; McCallion & Tobin, 1995, Bibby et al., 2012) suggest that negative interactions between parents and service providers can pose a major barrier to parents being willing to develop plans that rely on the formal service system. Service providers should attempt to foster positive and supportive relationships with parents and their offspring with intellectual disabilities that help these individuals feel that their needs and concerns are being listened to and adequately addressed when engaged with the challenging task of developing future plans.

8. Place greater emphasis on drawing on parents' unique knowledge base when developing policy and considering changes to the service system

The important insights offered by the participants who took part in this research highlight the tremendous knowledge that parents hold regarding supporting individuals with intellectual disabilities and their families. It seems logical for policy makers and service providers to draw on this wealth of knowledge as they attempt to develop services that will best support these parents and their offspring with disabilities. Ultimately, such an approach will not only help to ensure that the services that are being provided accurately reflect the needs and experiences of this population of parental carers, but will also help parental caregivers to feel that they have had input into the policies and practices that affect their day to day lives.

9. Target services toward supporting sibling carers.

As increasing numbers of typically-abled offspring are taking over caregiving responsibilities for their siblings with intellectual disabilities (Davys & Haigh, 2007; Heller & Arnold, 2010), it is crucial that policy makers place emphasis on supporting these next-of-kin successors. Current research suggests that many sibling carers are largely unfamiliar with the service delivery system when they are required to step into the role of overseeing the care of their siblings with disabilities (Heller et al., 2007; Heller & Kramer, 2009). With this in mind, greater emphasis needs to be placed on providing siblings with information on services, support with future planning, financial issues, and leisure and residential opportunities (Heller & Kramer, 2009). Moreover, as Benderix and Sivberg (2007) note, early intervention programs should be established to ensure that sibling carers have necessary information and skills prior to assuming responsibility for their sibling with an intellectual disability. A meaningful point of intervention for local service providers might be to encourage parents to anticipate transitioning caregiving responsibilities to typically-abled offspring very gradually. Such a graduated process of transitioning responsibility for care would afford valuable opportunities for identified successors to recognize gaps in their knowledge, and to identify concerns and questions while the primary caregiver (i.e., the parent) is still in a position to provide advice and guidance.

10. Consider how current research findings might be used to inform psychological practice with individuals with intellectual disabilities and their families.

The findings from this research suggest that the future planning process can be a challenging, and at times, very emotionally-charged, undertaking. With this in mind, greater attention should be paid to the role of the clinical psychologist in helping families navigate this often difficult task. For instance, clinical psychologists could utilize their understanding of behaviour change principles (i.e., Stages of Change Model – Prochaska & DiClemente, 1983) to assess a parental caregiver's readiness to begin developing future plans. By utilizing such a framework, clinical psychologists might then be able to draw on psychotherapeutic interventions (e.g., motivational interviewing strategies) to help parents progress towards future planning behaviour. Beyond helping to increase families' readiness to engage in planning, clinical psychologists could play a key role in assisting families in negotiating a shared vision for their future plans. Clearly, such assistance could be particularly valuable in instances in which family members have disparate ideas regarding appropriate future plans for their loved one. Finally, clinical psychologists could also play a very meaningful role in helping families adjust to the transitions that often occur as plans are created and enacted (e.g., the death of a parent, moving out of the family home, shifting relationships between siblings, etc.).

11. Families not currently in contact with the formal services should be viewed as a priority group for planning assistance.

Findings from this research, as well as from other studies (i.e. Harker & King, 1999), suggest that a lack of familiarity with the formal service system poses an additional challenge to engaging with the future planning process. Perhaps unsurprisingly then, families who are unknown to the formal service system often only become visible at a point of crisis (i.e., when a parent die or is no longer able to provide care). With this in mind, policy makers and service providers should place emphasis on trying to engage these "hidden populations" (Jokinen, 2008). To connect with minority populations, which research suggests are currently disproportionately underserviced (Heller et al., 2007), service providers should consider increasing awareness about available services in ethnic and/or religious communities. Moreover, where possible, service providers should consider how services might be modified to better fit the needs of these groups.

Limitations and Strengths of the Current Project

This research project utilized a qualitative design in order develop a richer understanding of parental future planning. The procedures that were used to enhance the rigour of this work are discussed in Chapter 3: Methods. Within this section, the limitations and strengths of this study are outlined.

While the researcher took steps to develop a methodologically sound research project, there were, nonetheless, a number of limitations in this study. It is important to note, however, that many of these limitations are ones that are commonly found in studies using the form of qualitative methodology that was utilized in the present project (Thorne, 2008). To begin, this study utilized purposive sampling, which was limited to the geographic location of British Columbia. As a result, the findings of this project – though interesting – cannot be generalized to the population of parents of adults with intellectual disabilities as a whole. It is worth noting, however, that many of the findings of this project are largely consistent with the findings of other studies on parental future planning conducted in other geographic areas, including Australia (Bigby, 1996, 2011), the United States (Heller & Arnold, 2010), and other parts of Canada (Joffres, 2002; Weeks et al., 2009).

Another significant limitation of this study is the fact that participants self-selected into this research, likely resulting in a biased sample. Specifically, after seeing some form of recruitment material (e.g., an email or a posting on a website explaining the study's focus on parents' experiences with future planning), people who were interested in participating contacted the researcher. It is possible that people who were more interested in, or open to, developing future plans were also more likely to self-select into a study focused on future planning. Conversely, those who did not self-select to participate in this research may have been more resistant to making future plans. This could serve as one possible explanation for the high rates of planning that were observed in this study. However, as noted above, the observed high rates of planning could also be attributed to the fact that, unlike many other studies, the concept of future planning was operationalized as including both formal and informal types of planning.

A biased sample may also have resulted from the recruitment procedures that were used. Specifically, the researcher attempted to recruit through both disability-specific services and more general services; however, disability-specific services were generally more open to disseminating and/or posting information about the study. Perhaps as a result of these recruitment challenges, the sample that was obtained seemed fairly heavily weighted towards parents who were already connected with various disability services and supports. Ultimately, this could have had a substantial impact on the patterns of future planning that were observed in this research.

In discussing the limitations of this study, it is also important to note the possibility of cohort effects. The parents who participated in this research ranged in age from 46-77 years; therefore, the oldest and youngest participants were separated by 31 years – meaning that several cohorts of older people were included in the sample. Given the marked changes in societal beliefs over the last several decades regarding how individuals with intellectual disabilities should be treated, it is likely that there were significant differences in the environmental and social factors faced by the different generations of parents who took part in this project; which, likely would impact their approach to future planning. Ultimately, these cohort effects likely restrict the generalization and predictive value of the findings of this research. With these cohort effects in mind, Haley and Perkins (2004) note that more research is needed that targets specific subgroups of older parents, such as those in different age groups.

Despite certain limitations, this research project also had a number of important strengths. Overall, the qualitative research methodology utilized in this study proved to be a useful means of gaining valuable information regarding parents' real-life experiences with future planning. Such an approach allowed for a much more nuanced understanding of this phenomenon, and enabled the "voices" of participants to be expressed; this added a level of richness and depth to the current findings that likely would have been lost in a more quantitatively-focused study. Ultimately, the methodology used in this study allowed for important information regarding how and why parents plan in particular ways to be obtained, and thus, helped to significantly extend our shared understanding of parental future planning.

These findings, in turn, will serve as useful points of departure for a number of important lines of future inquiry.

A final, very significant, strength of this study is its apparent benefit to many of the parents who participated in this research. Specifically, a number of participants spontaneously shared at the end of their interviews how helpful they had found the interview to be. These individuals noted that the interview had provided them with a useful opportunity to clearly articulate their planning process, their values related to planning, and their reasons for choosing to plan in a given manner. These participants highlighted how the act of planning can sometimes feel like a disjointed series of steps, and that having the opportunity to reflect on their planning within the interview helped parents see their plans more fully. With this in mind, two of the parents in this study even requested transcripts of their interviews because they were so pleased with the clarity with which they were able to articulate their future plans during the interview.

Conclusions

By extending the definition of future planning to include more than just a circumscribed set of discrete planning actions (e.g., making a will, establishing a trust, putting a child's name on a wait list for services), this research captured a wide range of parental future planning experiences that have, up to this point, been largely overlooked in the literature. Ultimately, this broadened focus yielded important information regarding how parents plan in real-life practice, and regarding the factors that may be associated with parents planning in particular ways. These research findings represent a sizeable contribution to the body of literature related to parental future planning. These findings highlight important avenues for future research, and draw attention to ways in which the formal service system might be changed to better facilitate and support parental future planning.

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Appendix A
Future Planning Approaches Questionnaire

1. What is your age? _____________

2. What is your gender? ________________

3. What is the age of your adult child with an intellectual disability? _______________

4. What is the gender of your adult child with an intellectual disability? _____________

5. Approximately what is your total household income? __________________

6. Approximately how many years of education have you received? __________________

7. What is your ethnicity? _______________

8. Martial status? _______________

9. After reviewing the "**Description of Future Planning Approaches**" document, please indicate which future planning approach(es) you have engaged in when planning for the future of your adult child with an intellectual disability by placing an "X" next to relevant approach(es):

__________ Concretized, detail-oriented planning

__________ Key person succession planning

__________ Social network planning

__________ No planning

If you indicated "No planning" please skip to question 13.
10. On the lines below, please briefly describe what your plan for the future of your child looks like (i.e., Who is involved? How detailed it is? For what areas of the care-recipient's life have you engaged in planning?):

____

____

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11. What do you perceive to be the major benefits of the future planning approach(es) you have utilized?

12. What do you perceive to be the major drawbacks of the future planning approach(es) you have utilized?

13. Are willing to be contacted by the researcher at a later date for a follow-up phone interview in order to discuss your experiences with future planning in more depth? (Please note that you are under no obligation to agree to follow-up contact, and indicating that you would be open to this possibility does not guarantee that you will be contacted)

____Yes ____No

14. If you indicated “Yes” to #13, please provide the following information:

Name:

____

Telephone number:

____

The best time to contact me is:

____

THANK YOU FOR YOUR PARTICIPATION!!!

Once you have completed this questionnaire, please be sure to save your answers and then email the completed questionnaire back to the researcher at cainesm@uvic.ca

Appendix B
Sample Interview Questions

1. Prior to starting the interview, I want to get a bit of basic demographic information about you….

    a. Caregiver's age/gender
    b. Care-recipient's age/gender
    c. Total household income
    d. Years of formal education
    e. Ethnicity/ethnicities that you identify with
    f. Marital status

2. To start off, can you tell me a bit about your caregiving situation?

    a. How old are you? How old is your child?
    b. What is your child's level of impairment?
    c. What does your role as "caregiver" currently look like? (i.e., what kind of tasks/responsibilities does it entail?)

3. On the questionnaire, you indicated that you utilized the ______________________ approach to future planning. Can you tell me in a bit about what exactly that looks like for you?

    a. Paint a picture for me of what you think the future you've planned for your child will look - in 10 years, in 20 years…

4. Prior to creating this plan for the future of your child, what other options did you consider? OR did you consider other options?

    a. How did you learn about these options?
    b. Who did you seeks advice or guidance from when embarking on the future planning process?
    c. How long ago did you start considering the need to future plan? When did you start looking into all of this?

5. Can you give me a sense of why, perhaps after considering other types of future planning, you chose to go about future planning in the way you did?

    a. What kind of things did you weigh and consider as you planned?
    b. Were there particular things about yourself that made you choose this form of future planning?
    c. Were there particular things about the care-recipient that made you choose this form of future planning?
    d. Were there particular things about your family context that made you choose this form of future planning?

   e. Were there any past experiences you had, perhaps with the formal service system or with your own informal support network, that influenced the way you chose to plan for the future?

6. The purpose of this research is to gain a better understanding of the reasons that parental caregivers might choose to select one form of future planning over another; do you feel like there is anything more you would like to add? Is there anything we have missed?

Appendix C
Text for Requesting Dissemination of Research Study Information

Dear ___________,

I am a doctoral student in the Clinical Psychology Program at the University of Victoria. For my dissertation, I am examining the different ways that parental caregivers of adults with intellectual disabilities plan for the future of their child, particularly looking at whether there are factors that may distinguish between caregivers who engage in more formal, concrete planning and caregivers who engage in more flexible, informal types of planning. As the first phase of this research project, I intend to administer a brief electronic questionnaire to parental caregivers of adult children with intellectual disabilities. With a subset of participants who indicate being open to follow-up contact, I also will conduct phone-interviews in order to gain a more fulsome picture their respective future planning processes.

I have been involved in past research that has focused on caregivers, and I know that recruiting these extremely busy participants can be challenging. That said, I am wondering whether _________________________ would be open to helping with the recruitment process by allowing flyer or posers to be placed in your main office and/or to circulate information about the research study to your email lists. Attached is a research letter outlining the study that is intended for potential participants, along with a detailed consent form. Please feel free to pass this along to anyone who you think might be interested.

If you have any question about this research feel free to contact me by email or at 250-858-5836 or to contact my supervisor, Dr. Holly Tuokko, at 250-721-6350.

Sincerely,

Megan Caines, M.Sc.
Psychology Department
University of Victoria

Appendix D
Research Letter

Factors Associated with the Selection of Future Planning Approaches by Parental Caregivers of Adults with Intellectual Disabilities

Dear Caregiver,

Thank you for expressing an interest in participating in my research project, aimed at exploring the factors that are associated with parental caregivers selecting particular approaches to planning for the future of their adult children (i.e., 19 years of age and older) with intellectual disabilities (i.e., significant limitations both in intellectual functioning and in adaptive behaviours, which extends to a variety of social and practical skills). **If you are the parent of an adult child with an intellectual disability, you are eligible to participate.**

While research in the area of intellectual disabilities overwhelmingly emphasizes the importance of parental caregivers planning for the future of their children, serious gaps still remain with respect to our understanding of the future planning process. For example, while several future planning approaches have been developed as ways of aiding parental caregivers in planning for the future, to date, no research has explored the various reasons or factors caregivers consider when selecting a particular approach to future planning. Parental caregivers who have engaged in some form of future planning have important information to share that could be instrumental in helping to develop ways of better assisting and supporting caregivers as they face the challenging task of planning for the future of their loved ones.

Participating in this research involves completing a brief electronic questionnaire, which will be emailed to you once you have emailed the researcher the signed and dated consent form (see attached). The questionnaire will take approximately 20 minutes to complete. In addition, if you agree to it, there is the possibility that you will be contacted at a later date by the researcher for a follow-up audio-recorded phone interview. The phone interview will take approximately 60-90 minutes. You are under no obligation to agree to follow-up contact, and indicating that you would be open to being contacted at a later date does not guarantee that you will be contacted.

I am a graduate student in the Clinical Psychology Program at the University of Victoria. If you have any questions to ask me before agreeing to participate, please phone me at (250)-858-5836 or email me at cainesm@uvic.ca. My academic supervisor is Dr. Holly Tuokko, Department of Psychology, University of Victoria. She may be contacted at (250)-721-6350.

If you are interested in participating, please review and complete (i.e., type your name and date at the bottom of the form) the attached consent form and then email it back to me cainesm@uvic.ca. Once I have received your completed consent form, I will email you the questionnaire. If you share your caregiving responsibilities with a spouse, feel free to jointly complete the questionnaire with him or her; **please submit only one completed questionnaire per household.** Thank you for considering this research project. I look forward to hearing from you.

Yours truly,

Megan Caines, M.Sc.

Appendix E
Consent Form

[Your department letterhead] ***Participant Consent Form***

Factors Associated with the Selection of Future Planning Approaches by Parental Caregivers of Adults with Intellectual Disabilities

You are invited to participate in a study entitled **Factors Associated with the Selection of Future Planning Approaches by Parental Caregivers of Adults with Intellectual Disabilities** that is being conducted by Megan Caines.

Megan Caines is a PhD student in the Department of Psychology at the University of Victoria and you may contact her if you have further questions by emailing cainesm@uvic.ca

As a graduate student, Megan is required to conduct research as part of the requirements for a degree in Clinical Psychology. It is being conducted under the supervision of Dr. Holly Tuokko. You may contact my supervisor at (250) 721-6350.

Purpose and Objectives

The purpose of this research project is to explore the possible factors associated with selecting different types of future planning approaches when parental caregivers plan for the future of their adult child with an intellectual disability. We also hope to gain an understanding of the process through which parental caregivers decide on a particular future planning approach, or combination of future planning approaches. To this end, we intend to administer a brief questionnaire, and to conduct interviews.

Importance of this Research

Research of this type is important because by exploring whether there are factors associated with selecting different types of future planning (i.e., more formalized, concrete forms of planning versus more flexible forms of planning), it may be possible to gain some sense of whether certain future planning approaches are better suited to particular types of families and/or caregiving situations. Such an understanding could help health professionals in better assisting and supporting parental caregivers as they plan for the future of their loved ones.

Participants Selection

You are being asked to participate in this study because you are a parental caregiver of an adult child (i.e., 19 years of age or older) who has an intellectual disability. You either received an email describing this research project and containing this consent form, or you contacted the researcher after seeing an advertisement or poster requesting volunteers who are parental caregivers of adults with intellectual disabilities.

What is Involved

If you agree to voluntarily participate in this research, your participation will include completing a brief electronic questionnaire, which will be emailed to you. You will be asked to complete the questionnaire electronically, and then to email the questionnaire back to the researcher once it is completed. The questionnaire will take approximately 20 minutes to complete. In addition, if you agree to it, there is the possibility that you will be contacted at a later date by the researcher for a follow-up audio-recorded phone interview. The phone interview will take approximately 60-90 minutes. You are under no obligation to agree to follow-up contact, and indicating that you would be open to being contacted at a later date does not guarantee that you will be contacted.

Inconvenience

Participation in this study may cause some inconvenience to you, in terms of the amount of time (as outlined above) taken from your usual activities.

Risks

There are no known or anticipated risks to you by participating in this research.

Benefits

The potential benefits of your participation in this research are that the results will inform health care practice, and, in turn, provide information concerning the best ways to go about supporting parental caregivers as they engage in the future planning process.

Voluntary Participation

Your participation in this research must be completely voluntary. If you decide to participate, you may withdraw at any time without any consequences or any explanation. You have the right to decline answering any questions in the questionnaire, and you may do so without prejudice. At the end of the questionnaire, you will be asked whether you would be open to being contacted at a later date for a follow-up audio-recorded phone interview. As stated, you are under no obligation to agree to follow-up contact and indicating that you would be open to this does not guarantee that you will actually be contacted. You have the right to decline answering any questions in the follow-up interview. If you withdraw from the study during the phone interview, you will be asked whether we may use your data up to that point in the discussion; if you would prefer not, your data will not be used and you will not be expected to provide any explanation for your decision.

Anonymity

In terms of protecting your anonymity, your name will not appear in any publications or presentations about this research. In addition, if you participate in a phone interview, we will change your name and any identifying information when the audio-recording is transcribed.

Regarding the individual to whom you provide care, questions will be limited to obtaining information regarding their disability (e.g. diagnosis, level of impairment).

At no time will you be requested to disclose the person's name or any other identifying information. As stated, you have the right to decline answering any questions that you do not feel comfortable answering. Any identifying information about this person that is disclosed in the interview and/or questionnaires will be changed if the audiotape is transcribed. Finally, the person's name will not appear in any publications or presentations about this study.

Confidentiality

Your confidentiality, the confidentiality of the individual to whom you provide support, and the confidentiality of the data, will be protected by storing questionnaire data and transcripts on a password-protected computer. Tapes from the audio-recorded phone interviews will be stored in a locked filing cabinet. Only the researcher, her supervisor, the skilled researchers enlisted to verify qualitative data interpretation will have access to the data. No names or identifying data will appear in the transcribed data (if transcribed) or in any reports or publication written about this study.

Dissemination of Results

It is anticipated that the results of this study will be shared with others in the following ways. Findings will be presented in the form of the researcher's doctoral dissertation, and through a presentation or poster in a scientific venue. In addition, manuscripts will be prepared for publication in peer-reviewed journals.

Disposal of Data

Data from this study will be disposed of by erasing the tapes and shredding the transcripts on or before January 1, 2019. Until the time of disposal, data will be stored as outlined above (see: Confidentiality)

Contacts

Individuals that may be contacted regarding this study include:

Megan Caines, M.Sc.	250-858-5836	email: cainesm@uvic.ca
Dr. Holly Tuokko	250-721-6350	email: htuokko@uvic.ca

In addition, you may verify the ethical approval of this study, or raise any concerns you might have, by contacting the Human Research Ethics Office at the University of Victoria (250-472-4545 or ethics@uvic.ca) or by contacting the Vancouver Island Health Authority Research Ethics Office (250-370-8260).

Your signature below indicates that you understand the above conditions of participation in this study and that you have had the opportunity to have your questions answered by the researchers.

____________________________ _______________________

Name of Participant *Date*

Appendix F
Description of Future Planning Approaches

Please read the following descriptions of different approaches to planning for the future of an individual with an intellectual disability. Consider which approach, or combination of approaches, best represents the form of planning you personally have engaged in when preparing for the future of your adult child with an intellectual disability.

Concretized, detail-oriented future planning

Caregiver develops comprehensive, concrete plans relating to the future care of their care-recipient with an intellectual disability (aka. "blueprints for the future"). This form of planning typically involves three major tasks; namely, formalized financial arrangements, formalized guardianship arrangements, and the creation of detailed residential plans (e.g., placing the care-recipient's name on a waiting list for residential care, transitioning the care-recipient from in-home care to supported accommodation, arranging support for continued living in the community). The hallmark of this form of planning is that the plans created by the caregiver are generally thought of as permanent and unchanging (i.e., the created plans are meant to sustain and support the adult with an intellectual disability throughout the remainder of his or her life).

Key Person Succession Planning

Caregiver intends the planned transfer of responsibility for overseeing the well-being of their child with an intellectual disability to a nominated key person. Such planning will vary in its level of formality and structure; in many instances these plans may be quite vague and "minimalist" in detail. The responsibilities of nominated key people vary from situation to situation; however, their roles often involve such tasks as financial management, decision-making, negotiation, coordination, mediation with services, supervision, and sometimes primary care. At the heart of this approach is an identified individual (i.e., nominated key person) who will be able to deal with unforeseen contingencies as they arise in the future life of the adult with an intellectual disability.

Social Network Planning

Caregiver seeks out and involves members of the care-recipient's broader informal support network in the planning process, and in supporting the individual with intellectual disability when the caregiver is no longer able to provide care. While group size and composition will vary from situation to situation, at the heart of such an approach is bringing together a group of people who all share the common vision of supporting the individual with an intellectual disability. Generally, group members carry out functions that are hard for the adult with special needs to manage alone (e.g., practical help with housing, employment, and recreation, developing closer ties to neighbors and the larger community). At times, an external organization (i.e., Planned Lifetime Advocacy Network) may assist the caregiver in creating, managing, and maintaining the social network.

Appendix G
Email Instructions for Caregivers for Completing Questionnaire

Dear Caregiver,

Thank you for agreeing to take part in this research!

Attached to this email are two documents:

1. The Future Planning Approaches Questionnaire

2. The Description of Future Planning Approaches for Caregivers document

You will need to review the Description of Future Planning Approaches for Caregivers document prior to completing questions 9-12 on the questionnaire. If you share your caregiving responsibilities with a spouse, feel free to jointly complete the questionnaire with him or her. **Please submit only one completed questionnaire per household.**

Once you have completed the questionnaire (expected completion time of 20-30 minutes), be sure to save the changes you've made to the document, and then email the completed questionnaire back to me at this address (cainesm@uvic.ca).

Sincerely,

Megan Caines, M.Sc.
Department of Psychology
University of Victoria

Appendix H
Email Indicating that Questionnaire has been Received

Dear Caregiver,

This email is to notify you that your completed questionnaire has been received.

Thank you again for taking the time to participate in this research project. The insights you have shared will be valuable in helping us gain a better understanding of the way in which parental caregivers plan for the future of their adult children with intellectual disabilities.

If you desire further information about the future planning process, you may find the Planned Lifetime Advocacy Network website useful (www.plan.ca). This website, which has been created for caregivers, provides information about the major elements of future planning, and suggests further reading and workshops that may aid you in planning for the future of your loved one.

Sincerely,

Megan Caines, M.Sc.
Department of Psychology
University of Victoria

Appendix I
Phase 1 Verbal Consent Script Prior to Initiating Phone Interview

Hello _______,

Prior to beginning our interview today, I just want to take a couple moments to revisit the issue of informed consent with you.

The purpose of our discussion today is to get a better understanding of your experience with the future planning process, particularly exploring the factors you weighed and considered when making decisions with respect to what your plans for the future would look like.

I anticipate that this interview will take somewhere between 60-90 minutes to complete. I really want to emphasize that you have the right to decline answering any questions I pose to you, and that you have the right to withdraw from the interview if you so desire. If you do elect to withdraw from the interview, I will ask you if I may use the interview data you've supplied up to that point; if you prefer that your interview data not be used, it won't be used.

This interview will be audio-recorded. This audio-recording will be transcribed by me at a later date. When the interview is transcribed, I will remove any identifying information related to both yourself and your child with a disability. In addition, neither your name, nor the name of your child, will appear in any publications or presentations that result from this research.

All of the data collected in this study will be stored securely. With respect to your interview data, the audio-recordings will be erased once transcribed, and the transcriptions will be stored in a locked filing cabinet and on a password-protected computer. Only myself, and my academic supervisor, will have access to this data. This data will be disposed of on or before January 1, 2019.

With all of that having been said, do you have any questions or concerns about this project and/or your participation in today's interview?