Eighteen and up: Researching disability and family quality of life in transition

by

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Abstract

This mixed methods study focused on how parents and primary caregivers perceive their family quality of life (FQOL) while a family member with intellectual and developmental disabilities (IDD) transitions from adolescence to adulthood. A modified version of the *Family Quality of Life Survey-2006 Short Version: Main caregivers of people with intellectual and developmental disabilities* (I. Brown *et al.,* 2006) queried families' perceptions and experience of their greatest strengths and supports, as well as their greatest needs and challenges in maintaining their family quality of life through this period of transition. In-depth individual interviews were conducted to further investigate the survey results and showed that participants struggled with a lack of support from others who did not share the experience of having an IDD family member while at the same time, they noted the high value they attribute to the support they receive from other families within the disability community who also have family members with IDD. Participants also noted the lack of support they receive from disability services and expressed the importance of finding opportunities for fulfilling their own needs, as well as the needs of other family members. These opportunities are reported as being essential to enhancing a variety of life domains, suggesting the need for more support in areas of family centred development. The implications drawn from these findings contribute to the discussion of changing how we view the domain support from others and how we can provide families with more opportunities to pursue areas of their own interest either individually or as a family unit in order to improve and enhance their FQOL as their family member with IDD transitions into adulthood.

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Acknowledgments

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Dedication

I would like to dedicate my study to families that continue to advocate for and work towards improving their families' quality of life.

Chapter One: Introduction and Context

In the past three decades, interest in family quality of life (FQOL) as an important area of study in the field of intellectual and developmental disability (IDD) has grown considerably (R. Brown, MacAdam-Crisp, Wang & Iarocci, 2006; Zuna, Brown & Brown, 2014). This surge in interest has been prompted by the closure of large institutions, the greater inclusion of individuals with disabilities into the community, and the increased expectations and responsibilities that have been placed upon families in the role of supporting and caring for their family members with IDD (Isaacs *et al.,* 2007; Rillotta, Kirby, Shearer & Nettelbeck, 2012). It is well established that families play an integral part in the lives of individuals with IDD and are crucial to their wellbeing (Knox, Parmenter, Atkinson & Yazbeck, 2000). It has also been found that happy, healthy and well-functioning families are better able to "facilitate and promote the wellbeing and growth" of individuals with IDD (Davis & Gavidia-Payne, 2009, p. 154). This recognition has led to the recent acknowledgement that the quality of life of all family members is connected (Knox et al., 2000). Each person is a part of their family and thus has an effect on the other members of the family and is reciprocally affected by them. As Brown and Faragher, (2014) note, "disability applies to the family as a whole and not just the individual with the disability" (p. 15). As such, in recent years, FQOL research has focused on the impact of disability within the family, acknowledging its effect on all members of the family, both as individuals and as members of a collective unit (Davis & Gavidia-Payne, 2009).

Research in FQOL has increasingly shown that FQOL is as a key issue arising from its "parent concept", individual quality of life (QOL), within the field of intellectual and developmental disabilities (Brown & Brown, 2004, p. 25). In previous reviews and studies of QOL, researchers found that parents and family members welcomed the focus on individual quality of life but expressed the need to have their own quality of life considered and for service providers and policy makers to understand the needs of the entire family (Burton- Smith, McVilly, Yazbeck, Parmenter, & Tsutsui, 2009; Isaacs *et al.,* 2007; Samuel, Rillotta, & Brown, 2012). Samuel *et al.,* (2012) note that in the past two decades there has been an increased reliance on families to take on more responsibility as carers, and to create partnerships with service providers in order to support and accommodate their family members with disabilities. With these augmented roles and responsibilities placed upon family members, Summers *et al.,* (2005) note, that it is important to ask the "question of accountability" and examine how disability impacts families and what supports and services would be most effective for them (p. 777). FQOL research developed with the aim of assessing what families' highest needs are and where these needs are being met, in order to determine the kinds of conditions that support higher family quality of life and develop "family centered approaches for support" (Schalock, 2004b, p. 21). Research concerning the development, measurement and application of FQOL for individuals with IDD and their families has recently been explored by researchers such as Juhásová (2015), Werner et *al.* (2009) and Zuna, Turnbull, and Summers (2009). Additionally, some areas of FQOL such as respite care, aging, family vulnerability, stress, and isolation from the

community have been specifically studied (Brown & Faragher, 2014). However, while interest has grown concerning FQOL, there is still a limited number of studies in this area when compared with the literature on individual QOL, especially where families with adult members with IDD are concerned (Bertelli, Bianco, Rossi, Scuticchio & Brown, 2011). There are many areas and aspects of IDD and FQOL that need to be further explored. For example, what aspects of family life such as relationships, careers, support from friends and services are affected, whether positivity or negatively, by disability as an individual with IDD ages? How do families optimize or enhance their quality of life? How do families function best and what supportive action should take place? What policies or services are needed and how can they provide the most effective support for individuals with IDD and their families? Therefore, to explore some of these questions, the present study looked to address parents and their perspectives on their families' quality of life while their child with IDD transitions from adolescence to adulthood.

Recent research has highlighted the complex and challenging process that families go through when their child with IDD transitions into adulthood. Families have described the period of transition to be "associated with stress second only to that experienced at the time of their child's initial diagnosis" (Dyke, Bourke, Llewellyn, Leonard, 2013, p. 149). Key challenges for families during this transition reported in the literature include: 1) a move from secure and generally supportive services, within the education system, to limited post-school services and new environments that lack consistency and require more independence (Strnadová & Evans, 2013); 2) a continual change in policies, programs and funding creating

feelings of uncertainty and instability (Dyke *et al.*, 2013); 3) a shift in the relationships and roles between parents and their children as well as differing opinions and expectations from each other (Cheak-Zamora, Teti, & First, 2015) and; 4) a lack of transition planning and service coordination, and parents exclusion from important aspects of the transition and planning (Davies & Beamish, 2009; Jivanjee, Kruzich & Gordon, 2009).

Jivanjee *et al.* (2009) find that there are few studies that have explored the perspectives of parents regarding family quality of life during this transitional period. Additionally, they note that those that do have focused only on the challenges and main stresses families are likely to encounter during the transition to adulthood. Within these studies the main focus appears to be on the parents' perceptions of the challenges their children face and their children's' quality of life. For example, the study by Dyke *et al.* (2013) focuses on parents' concerns for their children, such as their difficultly finding employment, their limited access to social and recreational activities and their difficulty of finding secured accommodation. Whereas Strnadová and Evans' study (2013) finds that parents are primarily concerned with their child's ability to continue developing friendships and social skills in new unknown environments, and want more support from education providers before the transition. Few studies were found that focus on parents' perceptions of their entire families' quality of life while their child with an IDD transitions into adulthood. Additionally, in their review of the literature about family quality of life, Samuel *et al.* (2012) state that many previous researchers have only asked, "why do families fail?" rather than also asking "how do families

succeed?" (p. 11). This thesis therefore examined how families that support and include individuals with IDD view and describe their FQOL. Specifically, this inquiry focused on parents or other family members' perspectives of their FQOL when a family member with IDD transitions into adulthood. Using a explanatory sequential mixed method approach including a well-established family quality of life survey and in-depth interviews, this study addressed the needs of families by focusing on their perspectives of their greatest strengths and supports, as well as their challenges and needs during their child's transition into adulthood. With the aim of exploring FQOL, this study sought to understand which supports, policies, or services families believe provide the most effective care and support to their family and what strategies they use to enhance their family quality of life.

Chapter Two: Literature Review

Quality of Life

Development of Quality of Life in Disability. Quality of life (QOL) is a "multidimensional concept" that over time has developed from a theoretical construct to a framework used in policy and practice in the field of intellectual and developmental disability (Schalock, 2004a; van Loon, Bonham, Peterson, Schalock, Claes, Decramer, 2013). In the 1980s and 1990s QOL was primarily used as a "sensitizing notion" (Brown, Schalock, & Brown, 2009; Schalock, Bonham, & Verdugo, 2008) that provided individuals with a reference and guide on the perspectives of individuals with disabilities, highlighting how they regarded themselves and the environment. The structure of QOL "grounded and guided what [individual's] valued and desired (Schalock, Bonham, & Verdugo 2008, p. 181), commonly including "feelings of wellbeing, positive social involvement and opportunities to achieve personal potential" (Park *et al.,* 2003, p. 268).

During the past few decades, the concept of QOL has expanded and developed in the field of intellectual and developmental disability. Claes, Van Hove, van Loon, Vandevelde, and Schalock (2010) explain that this expansion has occurred due to three primary sources: (1) a shift in perception from believing that "scientific, medical and technological advances alone would result in improved life," to an understanding that quality of life is a complex combination of "personal, family, community, and societal well-being" that is affected by personal "values, perceptions and environmental conditions" (p. 62); (2) secondly, there is an increased emphasis on the notion that community based services should provide

measured outcomes of an individual's life within the community; and (3) finally there is an acknowledgment of the importance of "person center planning, personal outcomes and self-determinations" (p. 62). With these shifts in understanding, quality of life has increasingly become an "agent for change" (Schalock, Bonham & Verdugo, 2008; Schalock, Verdugo, Bonham, Fantova, van Loon 2008, p. 276). Thereby, with its evolutionary nature, QOL has begun to shift society's perceptions of individuals IDD and supported us in reforming social and organizational practices and policies in order to enhance the well-being of persons with disabilities (Brown *et al.,* 2009) and their "QOL personal outcomes" (Schalock, Bonham, Verdugo, 2008 p. 181).

Over time, the concepts of QOL have evolved to include multiple roles and perspectives. In the late 1980's and 1990's researchers, including Andrews (1986), Renwick (1998), Schalock (1996) as well as parents, and self-advocates first established a framework for conceptualizing quality of life and its measurement and application (Schalock & Verdugo, 2012). This framework identified QOL as a multidimensional concept influenced by personal and environmental factors and their interactions. Within this framework a number of core ideas emerged regarding the conceptualization of QOL including: 1) there are many interconnecting elements of a life of quality and people know what is important to them; 2) QOL is different for each individual over time and between individuals, therefore factors such as culture, age, environment need to be recognized; 3) QOL is ever-changing; peoples' values, interests and ideas change with their environment and certain people, places and environments can influence and enhance an individual's QOL, as such QOL

should be measured in the context of these variables; 4) the choices individuals make in any one life stage can influence their choices and opportunities across their lifespan; 5) aspects of life and the environment are intimately connected and can influence each other, so the enhancement of one aspect of QOL may affect another; 6) one's perception of life is immensely important, but it is also important to take parents, spouses, and service providers suggestions and input into account when discussing and assessing an individual's QOL (Brown & Brown, 2003; Schalock *et al.,* 2002). Along with these core ideas, a number of conceptualizing principles were developed, most importantly that QOL "is important for all people and should be thought of [and used] in the same way for all individuals—those with and without disabilities" (Schalock *et al,* 2002, p. 460). Additional principles developed during this time include: (1) QOL is based on individuals' needs, choices, and control and; (2) is recognised as having both subjective and objective components and should therefore be measured using both qualitative (subjective) and quantitative (objective) techniques, (Schalock, 2004b). These core ideas and conceptualization principles provide a foundation for QOL measurement and application, which are outlined further in the following section.

During this developmental stage, the concept of QOL was also shaped into a framework for "service design and evaluation" (Brown *et al.,* 2009, p. 2). This framework developed into a "guiding principle for the transformation of human service organizations" (Schalock & Verdugo, 2012, p. 23), providing service providers with the knowledge they needed in order to improve their "performance and accountability" (Kober and Eggleton, 2009, p. 40). Van Loon *et al.,* (2013) note

this framework has immensely impacted organizations by "redefining the supports and services they provide" (p. 81).

    QOL Measurement and Application. As previously mentioned, over the past few decades, in the field of intellectual and developmental disabilities, the concept of QOL has been developed into a conceptual framework of measurement and application. Once QOL was established as a useful concept in the lives of individuals with disabilities, it developed into a basis for assessment and intervention (Brown & Brown, 2003). When gathering information, measurement of QOL requires multiple techniques and is commonly characterized as (a) being multidimensional; (b) having etic (universal) and emic (culture bound) properties; (c) having subjective and objective components; and (d) being influenced by personal and environmental factors (Schalock, 1996; Verdugo, Schalock, Keith, & Stancliffe, 2005). Claes *et al.,* (2010) add that QOL measurement is also characterized by its "incorporation of a systems perspective that captures [many of] the multiple events that impact individuals" and note that is it immensely important that individuals with disabilities, and people who know them well, are included in the design and assessment processes regarding their QOL (p. 62). In addition to these core characteristics there are three key QOL measurement principles that have been identified as essential when measuring individual QOL. These include: (1) measurement of QOL needs to involve life experiences and features that individuals highly value (Schalock & Verdugo, 2012), and consider the common and unique experiences people have in physical, social and cultural contexts; (2) measurement of QOL should enable individuals to move towards a meaningful quality of life that

they believe they can enjoy and value (Schalock *et al.,* 2002); and (3) measurement and application of QOL should enhance the wellbeing of individuals within their cultural contexts and use evidence-based practices (Schalock, Verdugo*,* Bonham, *et al.,* 2008).

From this conceptual framework of measurement, QOL models were developed as "blueprints" to help service providers and practitioners "understand and use the quality of life approach" (Brown & Brown, 2003, p. 99) Numerous models, from researchers such as Parmenter and Donelly (1997) and Cummins (2005), have been developed to explain the concepts and measurement of QOL in order to assist with assessment (Buntinx and Schalock, 2010; Lyons, 2010). These models were created with the purpose of assessing individuals' QOL based on specific personal measures or indicators in order to determine potential areas of growth and development (Claes *et al.,* 2010; Claes, Van Hove, Vandevelde, van Loon, & Schalock, 2012). Schalock, Bonham and Verdugo (2008) note that QOL models are used to guide organizations, implement QOL-related program practices, direct quality improvement strategies and "evaluate the effectiveness of those practices and strategies" (p. 182). Across these models, QOL domains, indicators and measurement principles are referenced with various similarities.

Adopted and promoted by an international group of researchers within the *International Association for the Scientific Study of Intellectual and Developmental Disabilities*, the QOL conceptual and measurement model proposed by Schalock (1996) is composed of three key components: factors, domains and indicators (Turnbull, Turnbull, Wehmeyer, & Park, 2003). Factors are higher order constructs

or primary aspects of life that are identified and universally held as important for a high quality of life, which Schalock, Verdugo, Bonham, *et al.,* (2008) note are believed to align well with personal well-being goals as well as public policy. The three factors are: independence, social participation and wellbeing. Following these factors, QOL domains are defined as the "multi-dimensionality of a life of quality" as they expand over a large range of personal aspects of wellbeing (Buntinx & Schalock, 2010, p. 287). Domains are comprised of eight QOL concepts including: personal development, self-determination, interpersonal relations, social inclusion, rights, emotional wellbeing, physical wellbeing, and material wellbeing (Schalock, Bonham & Verdugo, 2008). Finally, QOL core indicators are defined by Buntinx and Schalock (2010) as "perceptions, behaviours and conditions" that are related to QOL and are culturally sensitive, including aspects of life that are common to individuals across the world. Indicators are used to measure and assess QOL across the eight life domains, expanding on each domain and providing an indication of a person's wellbeing (Lyons, 2010; Schalock, Verdugo, Bonham *et al.,* 2008). Examples of some of the most common QOL indicators include: education status, behaviour choices and decisions, autonomy, social networks, social activities, interactions, relationships, community integration, human respect, dignity, and equality, safety and security, positive experiences, nutrition status, recreation, and leisure. Additionally, included within the model are QOL indicator items. These exemplary items are associated with each QOL domain and are used to measure QOL indicators and domains through self-reporting or direct observation.

With these well-established frameworks, models and measurement principles, researchers and practitioners began to focus on how to apply QOL and "translate the concepts into practice" (Samuel *et al.,* 2012 p. 3). With an emphasis on bringing about change, both on individual and societal levels, and enhancing the QOL for individuals with IDD (Schalock *et al.,* 2002), six core principles of application were established including: 1) use QOL as a sensitizing concept; 2) consider individuals lifespans when applying QOL as what is applied at one point in an individual's life may influence any subsequent points; 3) explore the perceptions of those involved (such as family members) but focus attention to the individual's own perceptions; 4) find out through observation and measurement what is important to the individual or family; 5) recognize that what may appear to be small concerns or aspects may be of great importance to the individual and; 6) understand that the individual and their family's wellbeing is enhanced by holistic practices (Brown, Schalock & Brown, 2009).

Brown and Brown (2005) note that organizations that carry out interventions or assessment services for individuals with disabilities need to recognize, understand and appreciate the core measurement and application principles and concepts of QOL, as they are essential to the effective application of quality of life. In the past three decades considerable progress has been made in the development and understanding of QOL and its significance in the lives of individuals with IDD is now well recognized. With this progress, the concept of QOL has expanded beyond the person, acknowledging the impact of disability on the whole family, and has influenced the service delivery system to pay specific

attention to the uniqueness of each individual with IDD and each of their family members (Park *et al.,* 2003; Schalock, 2004b). As QOL has continued to gain recognition in multiple ways and areas, Burton-Smith *et al.* (2009) have determined that the wellbeing and quality of life of families who are carers of individuals with intellectual and developmental disabilities also need to be considered. In the following section the development of family quality of life is outlined, exploring articles that examine and address the needs of families and family carers.

Family Quality of Life

> **Interest in Family Quality of Life.** Throughout the development of and research on individual QOL, it has been widely recognised that families play an integral part in the wellbeing of individuals with disabilities (Brown *et al.,* 2009; Samuel *et al.,* 2012). Correspondingly, it has been established that "the presence of disability has a major and diverse effect on family quality of life" (Brown *et al.,* 2009, p. 4). Family quality of life (FQOL) has become an area of interest and natural extension of individual QOL as families have steadily become recognized as the "main caregivers" of their adult children with IDD (Samuel *et al.*, 2012, p. 2.). Families have always played an essential role in supporting the adolescent and adult members of their families with IDD. However, as the trend towards deinstitutionalization has increased, the family home has correspondingly become the main and sometimes only available residence for adults with disabilities (Werner *et al.*, 2009). In turn, family members have continually been relied upon as the primary and constant source of support and have been required to undertake even larger degrees of responsibility for their family members with intellectual and

developmental disabilities. Although most families are willing to accept the increasing responsibilities as main caregivers and support units, many challenges arise that affect their family quality of life (Brown, Anand, Fung, Issacs & Baum, 2003). Therefore, many families are in need of assistance in helping them identify areas in their life that are important and in need of more support, and provide them with the appropriate polices, services and supports to enhance the quality of those areas.

The research on and application of family quality of life looks to (1) provide families with support so they can help themselves; (2) present families with numerous options so they can choose the supports they need and; (3) ensure families feel empowered so they can make the best choices for themselves and their children with IDD (Brown & Brown, 2004). FQOL focuses on the perspectives of individuals with IDD and each of their family members, individually and together as a whole, specifically focusing on their perceptions of their family life and what they value (Brown and Brown, 2004).

What makes a Family? Zuna *et al.* (2014) determine that families are considered a core and fundamental "unit of society across all nations" and are a principle structure for functioning and stable societies (p. 94). Werner *et al.* (2009) report that families are considered to be a social resource when they are functioning well and maintaining a "meaningful quality of life" (p. 502). However, over time the definition of what constitutes a family has continued to change. As the structures, functions and characteristics of families vary over time and across cultures and ethnicities, defining what a family is continues to be a particularly difficult task. In

view of this complexity, many studies on FQOL have chosen to use the definition

that researchers of the *Beach Center on Disability* developed (Brown and Faragher,

2014). They define family as "two or more people, who regard themselves as family,

who are closely involved in the day to day affairs of the others, who carry out

functions that families typically perform and who support each other on a regular

basis; whether related by blood, marriage or close personal relationship" (Samuel *et

al.,* 2012; Zuna *et al.,* 2014).

Ways of Conceptualizing Families. Knox *et al.* (2000) note that a family is

not just a collection of individuals but also a "complex and dynamic system" with

unique strengths, characteristics and needs (p. 17). Within each of these family

systems, each individual brings his or her own characteristics, idiosyncrasies,

desires and needs to that system. The *Beach Center on Disability's* definition of

family demonstrates how each family member is linked to the other, being impacted

and impacting their family members through their relationships. This is directly tied

to family systems theory, which outlines the importance of family interactions as

well as noting how significant families are in guiding the development of their

children (Davis & Gavidia–Payne, 2009). Each person within a family is part of the

whole, living individually but relating to each other, and the QOL of one family

member is linked to the QOL of other family members who surround them,

contributing to the entire family's QOL. Brown and Brown (2003) regard the family

as a 'meeting place' where the QOL of each family member meets together. Each

individual has their own unique QOL that involves their family's influences, however

their QOL also involves many outside influences that they bring back to their family.

This is further explored through Bronfenbrenner's bio-ecological theory of development. Urie Bronfenbrenner's evolved theory of human development takes into account that individuals are "both biological and social beings" (Howe, 2011, p. 246) and posits that an individual's development is primarily shaped by their relationships and interactions with various situations and surroundings in their environment (Patel, 2011). Within this theory there are complex overlapping and intersecting interactions between multiple systems of influence. These systems are depicted as centering around the individual in a nested layer of consecutively larger circles (Howe, 2011), beginning with the most immediate context of an individual, the microsystem. Within the microsystem are factors, personal characteristics, relationships, and activities that are associated with an individual's family, home, peers, school and neighbourhood (Bronfenbrenner, 1994). The microsystem is nested in the mesosystem, which involves the interactions of two or more settings or relationships within the microsystem, such as school – home interactions or parent – friend interactions. The next larger system that holds both the micro and mesosystems is the ecosystem, which contains the social system surrounding an individual and their micro and mesosystems. The ecosystem's influence which speaks to such life events as their parents getting a new job or their family moving, indirectly impacts an individual and is mostly beyond their control (Bronfenbrenner, 1994). Beyond the ecosystem is the macrosystem, which includes the cultural environment in which an individual develops, that is the beliefs, norms, and traditions that surround them as they age. Finally, all these systems are contained within the chronosystem, which is composed of events or transitions that

occur within the world over time (Özdoğru, 2011). Collectively, as individuals continue to grow and change they are continually affected by these surrounding systems, and the many overlapping interactions of these systems throughout their lifespan (Patel, 2011).

Using Bronfenbrenner's theory, the physical, emotional and psychological health and wellbeing of one family member that is influenced by factors both within and outside of the family, significantly contributes in facilitating growth and well-being in other family members, in an ongoing symbiotic cycle (Davis & Gavidia-Payne, 2009). As noted, a family is made up of collectively interdependent but independent parts that all bring their individual characteristics, experiences and influences home creating a "dynamic system of influence" (Brown & Brown, 2003, p. 179.) Therefore, a family can also be thought of as a unit with a surrounding system of influences and factors that affect it as a whole. For example, where the family lives, whether in a remote or urban area, can impact members individually as well as a unit (Brown & Brown, 2003). As such, an understanding of an individual's family quality of life cannot be formulated in isolation but needs to be viewed within the context of a family's environment including the internal and external influences of other family members, as well as the internal and external influences that affect the family as a whole. Every family has unique circumstances and influences, especially those with members with IDD. An individual with IDD like every other member of their family, is influenced and affected by all their family members, and correspondingly having a family member with a disability can affect many aspects of family life for the family as a whole, as well as affect various members of the family

in unique and different ways. Therefore, when exploring FQOL and looking at a family's needs and strengths, the many varying settings, perspectives, preferences and experiences of all family members separately and together must be considered.

FQOL Research. As previously mentioned, once research concerning QOL expanded, the focus turned to examining how disability influences and impacts families, as well as how enhancing the quality of life of families can influence and assist individuals with IDD and their individual family members. Research prior to 1990s focused on the negative impacts, such as increased stress, isolation, and burden of care (Issacs *et al.,* 2007 Park *et al.,* 2003). As well, that research tended to focus on mothers who usually took on the role of main caregiver (Rillotta *et al.,* 2010) and became deeply focused on the life of the child with IDD, which consequently impacts "family behaviour and lifestyle" (R. Brown *et al.,* 2006, p. 239). Although viewed through a deficit based lens, this research has led to key findings such as the understanding and acknowledgment that disability may unbalance family functioning as family members' interactions shift and tend to focus solely on the individual with the disability (R. Brown *et al.,* 2006). It also led to the recognition that families with members with disabilities are often marginalized and isolated from society, unable to partake in leisure and recreation or may be restricted in their family life activities together and independently (Bertelli *et al.,* 2011).

Understanding the range of challenges families face when a member has a disability is indeed important in determining areas of greatest need and support. However, as Phelps, McCammon, Weunsch and Golden (2009) state, a sole focus on

caregiver strain and stress, "only conceptualizes one piece of the caregiving experience" (p. 134). Having a child with IDD certainly presents many difficult challenges, but the presence of disability also provides family members with "reason to believe their lives have been enriched" (Brown & Brown, 2004, p. 5). As such, more recent studies have begun to use a family quality of life framework to explore how various aspects of family life are affected both positively and negatively by having a family member with a disability. This framework or approach has been developed to help researchers and service providers better understand all the perspectives and experiences of families in order to provide the most effective support (Isaacs *et al.,* 2007).

Recent research has revealed specific positive aspects and strategies for enhanced FQOL such as problem solving and positive coping (Brown, Kyrkou, & Samuel, 2016). For example, in a study by Burton-Smith, McVilly, Yazbeck, Parmenter, and Tsutsui (2009), participants, who were predominantly mothers, determined that while caring for a family member created notable limitations to their social networks, they did not consider caring for family members with disabilities as burdensome, and felt an increased sense of well-being when they received the necessary social support. In another study, parents of individuals on the autism spectrum reported that they gained a sense of family unity, and personal growth from caring for a family member with a disability (Phelps *et al.,* 2009). Thus, Rillotta *et al.* (2012) determine that findings such as these suggest there needs to be opportunities for families to expand their networks, embark on or re-establish their own interests and have greater access to important resources in order to re-

establish or enhance their quality of life. Additionally, Zuna *et al.* (2014) suggest that these and other positive outcomes illustrate how families find ways to live their lives positively day to day and find strategies for coping and resilience. In keeping with this, Samuel *et al.* (2012) describe the family quality of life approach as the "embodiment of a paradigm shift" (p. 3) as it builds on the strengths of individuals working together as a family when addressing the challenges they face (Phelps *et al.,* 2009).

Conceptualizing Family Quality of Life. With the increasing emphasis and recognition of the importance of family outcomes to both individuals with disabilities and their other family members, the construct of FQOL further developed and began to be viewed as a multidimensional concept with many of the principles and concepts that are similar to the conceptualization of QOL. For example, there are five principles that underpin the conceptualization of FQOL that are comparable to those of QOL. These principles state that FQOL is: (1) multidimensional and influenced by many factors; (2) comprised of generally the same dimensions for all individuals or groups, but some aspects may hold more importance or salience than others for some individuals or groups; (3) inclusive of both subjective and objective elements; (4) best studied using multiple methodologies (qualitative and quantitative); and (5) studied for the specific purpose of understanding and improving life for individuals with IDD and their families, specifically using their involvement in the design and implementation of QOL (Isaacs *et al.,* 2007; Samuel *et al.,* 2012).

As the construct of FQOL continued to develop, several initiatives emerged to

conceptualize a framework and develop measurement tools for a FQOL assessment approach (Isaacs *et al.,* 2007; Zuna *et al.,* 2014). *The International Family Quality of Life Project* began in 1997 and is one of two main initiatives created with the aim of examining and assessing the quality of life of families with individuals with IDD (Isaacs *et al.,* 2012). The purpose of the project was to develop tools and methods to explore families' perceptions of their quality of life in order to provide them with the resources that they need to enhance the quality of multiple aspects of their family life and make more effective support available to them.

Researchers from Canada, Australia, Israel and the United States conceptualized the notion of family quality of life and created The Family Quality of Life Survey[1] (FQOLS–2006; I. Brown *et al.,* 2006). This survey assesses family quality of life across nine areas or domains of family life. After thorough evaluation and field testing, the nine areas of family life included in this initiative's conceptualization are: health of the family, financial wellbeing, family relationships, support from other people, support from disability related services, influence of values, careers and preparing for careers, recreation and leisure, and community interaction (Rillotta, Kirby & Shearer, 2010; Werner *et al,* 2009). These domains were chosen based on literature concerning families with children with IDD and life domains from QOL (Issacs *et al.,* 2007), and form the "basis for conceptualising, measuring and applying FQOL" (Rillotta *et al.,* 2012, p. 72). Using the FQOL principles and family life domains, researchers developed a number of assessment

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[1] Further information on the FQOLS is provided in chapter three, as a modified version of the survey was used as a data collection method within this study.

indicators to provide assistance to individuals when identifying and expanding upon their family's wellbeing. The five indicators *The International Family Quality of Life Project* created and implemented into the FQOL-2006 survey are 1) importance; 2) opportunity; 3) attainment; 4) stability and; 5) satisfaction (Rillotta *et al.,* 2010). With the FQOL survey, the *International Family Quality of Life Project* aimed to give families a way to identify and vocalize aspects in their life that provide them with a meaningful quality of life as well as areas that need to be enhanced.

A second initiative, *The Beach Center of Disability,* based in The University of Kansas, focused their research on the "conceptualization, measurement and application of knowledge gained in the evaluation of disability services, policy and legislation" (Isaacs *et al.,* 2007). This initiative created The Beach Center Family Quality of Life Scale (FQOL Scale), (Hoffman, Marquis, Poston, Summers, & Turnbull, 2006) which though differing in some life areas and indicators, is comparable and complimentary to the FQOL-2006 survey tool (Zuna *et al.,* 2014). The Beach Center FQOL Scale includes 25 items based on five life domains including: family interaction, parenting, emotional wellbeing, physical and material wellbeing, and support for persons with disabilities (Isaacs *et al.,* 2007). Questions within this survey are designed to assess both the importance and satisfaction of the five life domains. Both assessment tools have been and continue to be used in numerous FQOL research studies; the Beach Center FQOL Scale across the United States and the International FQOL-2006 around the world in 19 countries (Isaacs *et al.,* 2012; Rillotta *et al.,* 2010). To date however, there have been few, if any studies that use these tools to focus solely on the QOL of families with a member with intellectual

and developmental disabilities that is transitioning from adolescence to adulthood.

Transition into Adulthood

  Moving into Uncharted Territory. Young individuals and their families face many challenges and obstacles as they progress from childhood, through adolescence into adulthood (Strnadová & Evans, 2013). Jivanjee *et al.* (2009) state that the transition into adulthood is characterised by movement towards "emotional, financial and residential independence" and often includes dealing with many obstacles and opportunities in employment and educational pursuits as well as more intimate and long-term relationships (p. 436). The transition into adulthood is viewed as a time of emotional turmoil as well as one of great excitement, as adolescents move into uncharted territory with "new social supports, friendships, autonomy and self-determination" (Dyke *et al.,* 2013, p. 149). However, for individuals with IDD, the process of transition has been found to be a longer and more difficult one than it is for their peers without disabilities.

  Hudson (2006) notes that many individuals with IDD and their families report that frustration, discontinuity, and confusion are common elements of their transition. A lack of options for employment and educational opportunities, a rapid change in environments and social networks, a loss of formal supports and a continual wait for services, accessibility, and funding are just a few of the challenges that adolescents with IDD face when transitioning into adulthood (Cheak-Zamora *et al.,* 2015; Dyke *et al.,* 2013). In addition, Chambers, Hughes, and Carter (2004) find that many individuals with IDD have difficulty finding appropriate and supportive accommodations and continue to reside with family members rather than accessing

more independent housing options of their choice. While there are many services in place for individuals with IDD during the transition process, Stewart *et al.* (2014) suggest that the focus of many services tend to be only on one domain of the transition such as health care, employment, accommodations or socialization, therefore ignoring the multiple and intersecting transitions and changes the individuals with IDD and their families are experiencing. Overwhelmed by future challenges and changes, many individuals with IDD in a study by Cheak-Zamora *et al.* (2015) reported that they prefer to focus on the present and therefore do not take the necessary steps towards transition, often getting left behind as their peers move into new careers, education, relationships, and other independent pursuits.

Experience of Transition for Families. All families encounter difficulties and "experience complementary transitions" as their children transition into adults, however for parents and families with family members with IDD, the obstacles and challenges they face are likely to be more complex and challenging (Jivanjee *et al.,* 2009, p. 436; Stewart *et al.,* 2014). The transition into adulthood for an individual with disabilities has been identified as an extremely stressful time, second only to when families originally receive the diagnosis of disability (Dyke *et al.,* 2013). Rather than being just one point in time, Strnadová and Evan (2013) note that the transition can be ongoing with continual issues, fears, and challenges.

Previous studies have examined the many challenges of IDD youth to adult transition for families, citing a lack of options, few opportunities, feelings of isolation and instability of services and systems. For example, parents in study by Dyke *et al.* (2013) reported challenges such as losing their own peer networks, struggling with

changes in their relationships with their children and community, anxiety during the long periods of waiting for a service or opportunity to become accessible and worry over complications as they and their family aged. Additionally, Brown, Geider, Primrose & Jokinen (2011), report that many families have stated that their family members are restricted in social relationships and participation in their communities. As the stress builds, the focus appears to continue to be on the individual with disabilities and the concerns and issues surrounding them, at times conflicting with the needs of other family members (Rillotta *et al.,* 2010). However, in spite of parent's continued support, increased responsibilities and apparent unwavering commitment, their perspectives on the transition and how it is affecting their child with IDD as well as themselves, other family members and the family unit altogether has received marginal attention (Dyke *et al.,* 2013).

It is well established that families are a key component for an individual with disabilities' success, especially during the transition into adulthood, however the family's perception of their own well-being, has been neglected in both research and practice. Additionally, of the studies that do seek out parents' perspectives, most highlight negative experiences, with only a few exploring parents' positive experiences and outcomes from their child's transition into adulthood. For example, in a study by Rapanaro, Bartu and Lee (2008), which focuses on positive and negative impacts for caregivers of individuals with IDDs, parents identified feelings of pride and personal satisfaction when they advocated for their child successfully. Parents additionally looked forward to and enjoyed when they had the ability to return to work or other interests when their children were able to access programs

and employment. In a slightly more recent study by Kuhaneck, Burroughs, Wright, Lemanczyk, and Darragh (2010), parents of children with autism spectrum disorders identified strategies and personal coping methods such as participating in support groups, finding opportunities for "me time" such as exercise or dinner with friends, and recognizing the joys in life and not taking things for granted (p. 344). Rapanaro *et al.* (2008) make note of how important it is that both negative and positive aspects are explored when researching how disability affects families as they suggest that identifying the positive aspects of a stressful or frustrating experience, or reassessing an experience in a positive light is actually an important way for parents to find meaning in their struggles and find strategies for coping.

Recent research and data on FQOL has finally begun to shed light on not just parents' concerns of their child with disabilities and their child's quality of life during transition, but also the quality of their and their other family members lives both individually and as a whole. However, literature specifically examining both the negative and positive outcomes for families with an individual with IDD that is transitioning into adulthood is still limited. As such, the present study provides an avenue for parents of individuals with IDD who are or have recently transitioned into adulthood to reflect on their FQOL.

Summary. This chapter reviews the development of individual QOL in the field of intellectual and developmental disabilities and examines how research has expanded to include FQOL, focusing on outcomes for each individual within the family and the family unit as a whole. With an emphasis on FQOL, this chapter also reviews literature regarding individuals with IDD and their transition into

adulthood, noting how this transition can affect and influence their and their families FQOL.

In response to shifting beliefs of individuals with disabilities and the acknowledgement that an enhanced quality of life is attainable for everyone, the field of intellectual and developmental disabilities has changed significantly and "embraced the concept of QOL" (Schalock, 2004b, p. 12). In the past three decades, the concept of QOL has developed into a social construct emerging from a point of reference that focused on how individuals regarded themselves, their experiences and their environments, into a multi-dimensional complex concept. Significant work has been done on QOL and growth in the conceptualization, measurement and application of QOL has resulted in multiple definitions, perspectives and approaches. Further, it is commonly accepted that an individual has a meaningful QOL when their needs are met, they feel included within their community and have social well-being, and the opportunity to achieve and attains goals that they set. But, while the concept of QOL has developed significantly over the past three decades, it has only been in the past decade and a half that there has been a corresponding focus on FQOL.

Due to several factors such as de-institutionalization, a growing demand on community services, and a reliance on family as the main caregivers and the family home as the main environment for adults with IDD, quality of life research has expanded to include the family and all its members' personal outcomes and wellbeing. Emerging as a natural extension of QOL, FQOL research developed with the aim of providing families with support so they can help themselves and make

informed choices from a variety of options and opportunities. Focusing on the importance of family for individuals with IDD as well as the impact of disability on the whole family, past research on FQOL explored the negative impacts of disability on FQOL. However, within the past decade research also began to examine the positive aspects of disability on FQOL.

Two main initiatives emerged, the *International Family Quality of Life Project* and the *Beach Center on Disability*, creating family quality of life scales to measure and assess FQOL. Although their survey tools focus on slightly different life domains, both have the objective of enhancing families' QOL and offering service providers the tools necessary to provide effective support and services. As previously mentioned, both survey tools continue to be used in research studies around the world, however, few studies were found that examine FQOL during a child with IDD's transition into adulthood.

Although the transition period has been reported as one of the most stressful and challenging times for families with a member with a disability, little research has focused on assessing FQOL during this time. The transition from adolescence to adulthood has been described as a time of both excitement and turmoil as individuals work to become more independent; however, for individuals with IDD and their families the transition time appears to be more of an ongoing period of frustration and confusion as barriers to housing, funding, employment and community inclusion continue to arise. During this time, the concerns and issues surrounding the individual with IDD continue to increase and the family may lose its sense of equilibrium impacting the FQOL of the entire family. There appears to be

little in the way of research on families' perceptions of their FQOL during this time

and much of this available research focuses on the negative aspects. Since there are

so few studies that specifically examine quality of life for families with individuals

with IDD who have or are transitioning into adulthood this study aims to address

this need and provide some exploration and data on this specific topic.

Chapter Three: Methodology and Methods

Theoretical Foundation

      Critical Realism. This study researched family quality of life (FQOL) and intellectual and developmental disability through the theoretical traditions of critical realism. Critical realism is an ontological framework that rejects the reductionism found in both social constructionism and postmodernism (Elger, 2010). It asserts that reality is complex, arising through multiple stratums of material and social conditions. In this paradigm, it is understood that humans have some agency in shaping their worlds, although their behaviours are simultaneously constrained by resilient social structures. The sociologist and philosopher Roy Bhasker is widely recognized as having established the theoretical foundations of critical realism (Houston, 2014). According to Bhaskar, reality can be conceptualized through a stratified ontology with three levels: the Real, the Actual and the Empirical. Taken in order, the Real encompasses the "causal properties and powers of nature" that contain the possibilities for an object's actualization (Elger, 2010, p. 254). Next, the Actual refers to those objects and events that *actually* occur within the world. Importantly, critical realism—contrary to social constructivism— argues that these actualities occur regardless of our interaction or awareness of them. Finally, the Empirical refers to actualities' observable qualities, *i.e.* the reality humans perceive through their senses (Clark, 2008). It should be noted that both the Actual and the Real cannot be experienced directly, and therefore, they can be "perceived only fallibly" (p. 168). As such, these dimensions of reality cannot be knowable with firm assurance, thus critical realism rejects the positivist view that

research can verify absolute findings. Critical realism recognizes one multi-layered reality but suggests that we as researchers do not have immediate access to it nor are we able to observe and realize every aspect of it. Therefore, as researchers we can only attempt to respond and understand reality through the Empirical, as it relates to the Real and Actual.

How does CR help us understand disability and family quality of life? Through a stratified ontology, critical realism asserts that reality holds open the possibility for continual change, for in this domain, unseen mechanisms are constantly operating creating a labyrinth of cause and effect, with some "mechanisms complimenting each other while others act in countervailing opposition" (Houston, 2014, p. 220). For example, each individual carries the potential to have or develop a disability, from birth or through an accident, illness, or otherwise. Additionally, age, environment, experiences, social structures and other tenets of causal reality work together to continually shape and configure an individual. These possibilities reside within the Real, of which our biological selves are a part. However, we cannot perceive *all* of the causal mechanisms that create a particular actuality, as there are entities that are independent of knowledge (Houston, 2014, Shakespeare, 2006). We cannot see the innumerable causalities that collectively create an individual's personality nor can we always anticipate an individual's perspective, opinion or behaviour. Most importantly, critical realism asserts that causality is never linear, but that it works synergistically (Houston, 2014). The emergence of some actualities will encourage or impede the emergence of others. With regard to an individual, only their empirical self, as biologically

experienced, offers evidence for major features in this underlying process. Whereas social constructivism and post-modern theories emphasize the power of language when considering disabilities' origins, critical realism encourages us to recognize its material foundation, as well as its concurrent social construction (Houston, 2014). For once empirically present, disability is open to the process of social construction, *i.e.* comparison, diagnosis, definition, and categorization. However, this constructivist process is never complete, for humanity's position within the Real holds open the possibility for continual change.

Humanity participates in the conditions of reality through agency (Elger, 2010). In other words, the social constructs arising through our empirical experiences are not passive translations of reality. Humanity remains a causal force across all stratums of reality, as "humans are conscious, intentional, reflective and active in constructing their world", as it is being constricted and shaped by causal underlying structures (Craig & Bigby, 2015, p. 312). With regard to the growth and development of families, all members of the family are affected individually and as a group by the disability of a family member. However, they are affected in different ways as their behaviours and lifestyles are influenced and impacted by a number of additional complex and multilayered possibilities within the Real. Critical realism links structure and agency together providing a basis for exploring the social and structural contexts that shape families' behaviours and expectations. As such when researching families, it must be understood that the research is taking place in an "open system" and that is it impossible to isolate and understand all mechanisms (Craig & Bigby, 2015, p. 314). Therefore, reflecting a critical realist foundation, this

study sought to explore and gain a deeper understanding of the processes that enable or constrict families and their FQOL while their children with IDD transition into adulthood while keeping in mind that many of the underlying mechanisms will remain unseen to both the researcher and the participants themselves.

Critical realism's stratified ontology encourages us to see disability as both socially and materially (*i.e.* physically) defined. Disability is a multifaceted concept that continues to develop and change, most significantly with the reconceptualization of what disability is within our society, how we respond to it and what needs to be changed in order for those with disabilities to gain full equality and equity. Traditionally, the medical model views disability as a defect that individuals should strive to overcome, hide or manage in order to be fully functioning humans (Iezzoni & Freedman, 2008). In contrast to the medical model, the social model determines that the problem does not lie within a person but with the environment that fails to accommodate them and therein is a result of a social organization that excludes individuals with disabilities (Priestley, 2010). The social model suggests that it is not the physical, mental, sensory, or cognitive impairment that causes disablement but the way in which our society "fails to accommodate natural aspects of variation and difference between people" (Priestley, 2010, p. 2). However, rather than focusing on disability as either a deficit or structural oppression, Shakespeare (2006) suggests that a more holistic approach should be taken. Watson (2012) notes that disability cannot be bound in one particular ideology, as it is far more complicated than any single model suggests. Shakespeare and Watson (2010) additionally note that such models produce only narrow

understandings of disability and neglect important aspects of life for an individual

with IDD and their lived experiences of themselves and those closest to them.

Disability and the experience of disability arise from the complex interactions

between an individual with disabilities, their intrinsic personal factors and their

social and physical environment (Shakespeare & Watson, 2010). Therefore,

research concerning disability should be attentive to the ways in which individuals

with disabilities and their families "define their own experiences and perspectives"

(p. 72) and engage with their surrounding environment. In this study, a critical

realist approach is linked with the previously mentioned ecological model and

family systems theories with the intention of bringing a more inclusive and

relational approach to the study of disability through a focus on learning what

matters to each person within the family by examining parents' and caregivers'

everyday life, experiences and perspectives while their child with IDD transitions

into adulthood.

Definitions

As there are various perspectives on and theories about families, disability,

and quality of life, it is important to define these terms as I have used them in this

study.

Parents. Similar to Jivanjee *et al.* (2009) the terms 'parents', and 'caregiver'

are interchangeably used in this study to "refer to a person with parenting

responsibilities for a young person" (p. 436).

Transition into adulthood. In this study, transitioning from adolescence to

adulthood is defined as a process of moving from the dependent and protected life

of a child to a more autonomous life as an adult. Individuals move through this process in various stages and rates, obtaining all or some of the adult social roles related to independence, employment, housing, relationships, education and self-determination (Dyke *et al*., 2013).

  Intellectual and developmental disability. There is an ongoing debate about how to "properly name, define, and assess IDD" (Salvador-Carulla *et al.,* 2011, p. 175). The question of how best to define IDD within the context and understanding of individuals, families, policy, environment, culture, medical diagnosis, eligibility and support remains a vehemently contested topic (Salvador-Carulla *et al.,* 2011). However, for the purpose of this study, intellectual and developmental disability refers to a broad range of disabilities and difficulties that are characterized by a singular challenge or a combination of impairments in cognitive development, intellectual functioning and adaptive behaviour. These difficulties or impairments emerge prior to birth or during the developmental years due to a variety of causes, interact with a variety of intrinsic and extrinsic factors and require support and consideration during all stages of the lifespan (R. Brown *et al.,* 2006). Examples of IDD that may be presented in this study include but are not limited to the following: Autism Spectrum Disorder, Pervasive Developmental Disability, Down syndrome, Prader-Willi syndrome, Fragile X syndrome, Williams syndrome, Rett syndrome, Phenylketonuria, Cerebral Palsy, and Fetal Alcohol Spectrum Disorder.

  Quality of life. Many definitions of QOL have emerged over the past three decades, as no single definition has been agreed upon as to what constitutes a life of

quality however, some key aspects have been commonly accepted (Brown, Cobigo & Taylor, 2015). Brown and Brown (2003), suggest that QOL occurs when an individual has a life that is meaningful to them and they are provided with the resources necessary to maintaining this meaningful life. Similarly, Brown and Faragher (2014) recently highlight Goode's (1994) definition of QOL noting that QOL is "experienced when a person's basic needs are met and [they have] the opportunit[ies] to pursue and achieve goals in major life settings" (p. 8). Although there is a wide range of QOL definitions, Turnbull, Turnbull, Wehmeyer and Park (2003) state that within the field of intellectual and developmental disabilities there are some commonly accepted aspects in all definitions including: 1) a general experience of feelings of wellbeing and happiness; 2) positive social involvement and acceptance and; 3) opportunities to reach and attain personal goals. For use in this study a combination of these definitions is used, noting that QOL occurs when an individual's life has value and is meaningful to them, and when they can maintain their meaningful life by having the resources necessary to create and attain personal goals and be surrounded by positive social environments.

Family Quality of life. As noted, FQOL is based on similar principles to QOL however they extend beyond the individual with the disability, capturing the needs of each person in the family as well as the family unit as a whole (Davis & Gavidia-Payne, 2009). Similar to Davis and Gavidia-Payne (2009) this study uses the definition of FQOL first provided by Park *et al.* (2003): FQOL is attained when the "needs of all family members have been met, when the family enjoys their time

together and when they are able to participate in activities that are valuable to them" (Davis and Gavidia-Payne, 2009, p. 153).

Research Questions

As previously noted, this study focused on family quality of life by examining the experiences and perspectives of families with individuals with IDD, as these families experienced their child's transition from adolescence to adulthood. The over-arching questions that structured this study are as follows:

1) How do families perceive their quality of life during their child's transition into adulthood?

2) What are families' experiences of family quality of life during this period? What are some of the notable changes that families experience in their quality of life when their child transitions from adolescence to adulthood?

3) What do families perceive as their greatest supports and strengths during their child's transition into adulthood?

4) What do families perceive as their greatest needs and challenges during their child's transition into adulthood?

5) How are families successful during this transition period?

6) What would be beneficial for families moving into the transition stage to know?

Research Outline

To answer the above questions, I used an explanatory sequential mixed methods approach. Creswell (2014) notes that this mixed method design involves two phases of data collection, the first phase collecting quantitative data and the

second phase collecting qualitative data to further explore the initial findings. This study incorporated a modified family quality of life survey from the *International Family Quality of Life Project* for the first phase of data collection, and in-depth interviews for the second phase of data collection. An explanatory sequential approach aims to capture the complexities of experiences and situations as it uses the results from the quantitative data collection to inform or build on to the qualitative data collection (Creswell, 2014). This approach is suggested to be useful to student researchers because one database builds on the other, however the long and time intensive nature of this method including obtaining and analysing both sets of data can be challenging (Creswell, 2014). In addition to the collection and analysis of both quantitative and qualitative data, certain quantitative results from this study were also compared with a family quality of life study by R. Brown *et al.* (2006). This was done to increase the validity of the study and to ascertain some of the similarities and differences of families' FQOL during different life stages.

Methodology

My choice to use a mixed-methods approach was motivated by two key factors. The first stems from the knowledge that the philosophical premises that are foundational to critical realism, the theoretical foundation that guided this study, are recognized as positioned midway between positivism and interpretivism (Zachariadis, Scott & Barrett, 2013) and embraces the use of a variety of methods from different perspectives. Therefore, using both qualitative and quantitative data collection methods and a multi-layered analysis, and combining descriptive and thematic analysis, adheres to a critical realist framework that is not constricted by a

one-pointed focus of either empiricism or constructivism. Secondly, a mixed-method approach draws on the strengths of both quantitative and qualitative research, minimizing their limitations (Creswell, 2014) and increases the credibility of this study as it provides avenues for; 1) complementarity; 2) clarification; 3) and triangulation (Hesse-Biber, 2010).

With regard to developing complementarity and clarification within this study, the Family Quality of Life Survey - 2006 provided the opportunity to gain general information concerning each family's background and their family structure, as well as the parent's perspectives on their FQOL when their child is transitioning into adulthood through both quantitative and qualitative means of data collection. Following the survey, the use of interviews gave parent participants the option to go into more depth with regard to themes that arose from the survey. While this study first intended to use focus groups as the qualitative data collection method, unforeseen circumstances determined that interviews would be more effective instead, which is discussed further in the qualitative measures section. The use of interviews following the FQOL survey allowed me to clarify certain points, ask follow up questions and gain additional information from participants. Overall, the data collection methods that I used were complementary as the results from the survey informed the questions and topics for the interviews, thus enhancing the reliability of the data.

Triangulation, which refers to the combination of multiple methods to examine the same question or set of questions, is another advantageous technique that I used in this study. Guest, MacQueen and Namey (2011) find that triangulation

provides opportunities to compare and analyze results to see if they are

complimentary or conflicting. Therefore, in addition to completing the FQOL survey

and participating in the interview discussions, participants were asked to read

through the written transcript of their interview to provide any extra comments or

responses. This process of transcript feedback was employed to increase or confirm

the validity of the information collected. Participants were given the opportunity to

confirm what they had said, make corrections and add in any additional

information. Taken together, these methods were aimed at providing more

comprehensive and trustworthy findings.

Participant Recruitment. I used a purposive approach for recruitment, as a

certain group of individuals were purposefully selected and the sample of

participants was tied to the study's objectives (Palys, 2008). Participants needed to

meet the criteria of being in a parental role, for example be a parent, family member

or individual who was recognized as the main caregiver, to an individual with

intellectual and developmental disabilities who was between the ages of 18-26 and

who had recently transitioned, or was currently transitioning into adulthood. I

aimed to recruit 25-30 participants for the survey, anticipating that 6-8 individuals

would also participate in the focus group. As the criteria for participation was quite

selective, I reached out to numerous agencies that provide services for individuals

with intellectual and developmental disabilities, for assistance in recruitment. Eight

disability agencies with transition to adulthood services that serve individuals in the

age range of 18-30 were contacted in the beginning of the study. An additional four

were chosen and contacted when participant recruitment proved to be slower than anticipated.

To facilitate rapport with key stakeholders within these agencies, a key member of a participating organization sent an introductory email to several of the other agencies in order to introduce me as the primary researcher and provide information about my study. I followed this up with an email with further information on the study and a letter (see Appendix A) requesting their assistance with the study, and providing them with my contact information. In this letter, agencies were told of the study's objective and were asked to send a participant invitation (pre-written by the researcher) to individuals within their organization that they believed fit the selection criteria. Of the twelve agencies contacted three responded and signed an agency approval form (see Appendix B), which in accordance with the University of Victoria's Human Ethics board confirmed their agreement to assist in recruiting participants. After signing the approval form, agency directors were sent participant invitations (see Appendix C), which they sent out to their families in the form of email, newsletter or on their social media outlets. If participants were interested in being a part of the study whether by completing the survey, attending the focus group or both, they were asked to contact me. Using this approach meant that the number of potential participants reached was unknown, however this decision was made to protect the privacy of the organizations' clients. As well, this approach ensured that potential participants would not feel pressured to take part in the study, as their participation in the study would remain anonymous. Once interested individuals contacted me and

volunteered to participate they were sent a survey package by mail. This package contained: an information and instruction page (see Appendix D), 2 consent forms (see Appendix E), one to sign and one to keep for reference, the *Family Quality of Life Survey (FQOL-2006) shortened version: For main caregivers for individuals with intellectual and developmental disabilities*, and a pre-addressed and stamped envelope so they could mail the signed consent form and completed survey back to me.

      Participants. During the approximately six-month long data collection period, ten families completed the Family Quality of Life Survey-2006. Of those ten families, six members of four families also participated in the interview discussions. Each family participant identified themselves as a parent or main caregiver of an individual with intellectual and developmental disabilities who was between the ages of 18-26 and who was currently or had recently transitioned into adulthood. Table (1) outlines the descriptive characteristics of family participants who completed the survey. Participants were mainly mothers with one survey completed by a father and one completed by a mother and father together. Participants' ages ranged from 48-61 years. Of the ten families that participated in the study, seven lived in two-parent households. Additionally, in seven of the families, the mother was the main caregiver, while in two families both parents shared the range of parenting responsibilities and in one family, the father was the main caregiver.

      Three of the ten families indicated a second individual in the family with a disability. Six of the family members with IDD had siblings. Of that group three lived at home with them and two acted as caregivers. With respect to family

responsibility and day to day affairs for the family, four participants indicated they had <u>much more</u> responsibility than they liked, three participants indicated they had <u>more</u> responsibility than they liked, three participants indicated they had the <u>about the amount</u> of responsibility they liked. For responsibility specifically related to the individuals with IDD, four participants indicated they had <u>much more</u> responsibility than they liked, four participants indicated they had <u>more</u> responsibility than liked, and one participant indicated they had <u>about the amount</u> of responsibility they liked. One participant indicated they <u>either</u> had <u>about the amount</u> of responsibility they liked or <u>more</u> responsibility than liked depending on the day with the comment, *"as a parent, one's energy levels ebb and flow".*

Table 1 *Participants*

Relationship to individuals with IDD	
Mother	8
Father	1
Mother/Father	1
Age of participants/parents in years	
Mean	55
Age Range	48-68
Family Structure	
One Parent	2
Two Parent	7
Other (Separated)	1
Number of Siblings for member with IDD	
Zero	4
One	2
Two	3
Three	1
Families with more than one individual with a disability	
	3

Individuals with IDD. Within these families there were five males and five

females with IDD. The primary diagnoses were intellectual disability – cause

unknown (4), Autism (4) and Down syndrome (2). Five individuals with IDD had

one secondary diagnosis including autism or pervasive developmental disorder

(PDD). Two individuals with IDD had tertiary diagnoses including sensory

processing disorder, obsessive-compulsive disorder, ADHD, and Tourette disorder.

In all instances, the individuals with the disability had other conditions such as

speech and language difficulties, sensory processing, sensory integration

impairment, obsessive-compulsive disorder (OCD), anxiety or heart problems. With

regard to the level of support needed, three individuals with IDD required support

for almost all aspects of life, five individuals required support for most but not all

aspects of life, and two individual required support for some aspects of life.

Additionally, five participants indicated that their children with IDD had additional

behavioural problems such as 'self-injurious and perseverative behaviours',

'anxiety', 'OCD', and 'angry outbursts'.

Quantitative Measures. Quantitative data was collected via the *Family

Quality of Life Survey (FQOL-2006 Survey) shortened version: For main caregivers for

individuals with intellectual and development disabilities* (I. Brown *et al.,* 2006). The

FQOL-2006 Survey was created by an international team of researchers, from

Australia, Canada, Israel, and the United States, and has been used in over 20

counties and translated into several languages (Giné *et al.,* 2015). The initial version

of the survey, published in 2000, has been extensively tested, evaluated and

modified, resulting in the current updated version. Guest *et al.* (2011) state that

evaluation practices such as receiving feedback from participants and revising and

retesting questions can benefit certain data collection methods such as surveys and

contribute to their validity as accurate and trustworthy measures. The FQOL-2006

survey is a tool used to access the quality of life of families who have one or more

members with an intellectual and developmental disability. The survey can be used

with any type of family regardless of age, education, structure or other

characteristics and is "lifespan sensitive" and can therefore be used with families

who have family members with IDD of various ages (Giné *et al,* 2015 p. 245). The

survey collects information using both quantitative and qualitative data collection

methods. Quantitative questions provide data for statistical analysis while

qualitative questions allow the researcher to further explore participants' FQOL and

gain a deeper understanding of the numbers with the quantitative results (Brown,

2010) The introductory section of the survey consists of background information

and family structure. Following this first section, are nine sections, each one

addressing a life domain including: 1) health of the family; 2) financial well-being; 3)

family relationships; 4) support from other people; 5) support from disability-

related services; 6) influence of values; 7) careers and preparing for careers; 8)

leisure and recreation; 9) and community interaction. Within each of the nine life

domains, six dimensions (or indicators) are used to examine how parents perceive

their family quality of life. These include importance, opportunity, initiative,

stability, attainment, and satisfaction. Quantitative data is collected on each of the

nine domains as participants assess these dimensions using a five point Likert Scale

that ranges from five (being very high with responses such as 'very important' and

'very satisfied') to one (being very low with responses such as 'hardly important at all' and 'very dissatisfied' to). Examples of some of the surveys quantitative questions are as follows: 'How important is it to your family's quality of life, for family members to pursue or prepare for careers they want?' and 'All things considered how satisfied are you with the disability related services your family receives?' Space for in-depth written responses is available in each of the nine sections for qualitative data collection, giving participants the opportunity to embellish on or further clarify their thoughts. The opportunity to add additional comments, information or explanations, facilitates valid responses from the participants, as they are not constrained by the researcher's multiple-choice answers. This further improves the validity of the survey (Guest *et al.,* 2011).

Authors of the FQOL-2006 survey provided me with permission to use and modify the survey for this study. As such, due to time limitations of the study, the survey was modified and some sections were removed. This was done with the intention of hopefully encouraging more participants to complete the survey as well as then take part in the focus group. Modifying the survey may have influenced the credibility and validity of the survey, however Park *et al.* (2003) state that use of the full version of the FQOL-2006 survey could create a "response burden" resulting in fewer willing participants (p. 379). As the population of potential participants was already limited, it was important to me that those individuals who did participate completed the survey and would be motivated to participate in the focus group. Therefore, with the support of my thesis committee, it was determined that the use

of a shortened survey would be beneficial to the study as it was anticipated that participants would be more likely to complete the full survey if it was succinct.

In order to shorten the survey, only four dimensions including importance, opportunity, initiative and satisfaction were used to assess the nine previously mentioned domains. These four dimensions were used to focus on the families' interaction with their environment and their perspectives on their family quality of life during their child's transition into adulthood. As this study focused on a specific period of time in the participants' lives, questions pertaining to attainment and perspectives on future quality of life were not used. Questions regarding stability and the degree to which participants enjoyed the various FQOL domains were also removed, as these questions were similar to questions regarding FQOL satisfaction. The modified survey used in this study was fifteen pages long, with thirteen questions regarding family structure, five questions for each of the nine life domains and seven questions regarding overall family quality of life.

Data that was generated by the modified form of the FQOL-2006 survey was analysed and summarized by using descriptive analysis with a focus on frequencies, commonalities and the numerical differences between participants' responses. Only ten surveys were completed in this study, therefore statistical analysis was not conducted, as there was not enough data to make generalized conclusions. However, select data was compared against another family quality of life study using Spearman's rank correlation (Rho), a non-parametric test to determine if there were any similarities or differences between the two studies. Thematic analysis was used to interpret the qualitative comments from the survey. This process is further

described directly below. The comments and the themes that arose from the qualitative survey data analysis were then used to help build the questions for the focus groups and were them compared with the quantitative data from those discussions to further explore and understand participants' responses.

Qualitative Measures. As noted above the *Family Quality of Life Survey (FQOL-2006 Survey) shortened version: For main caregivers for individuals with intellectual and developmental disabilities* was used to collect a portion of the qualitative data for this study through written responses. In addition to this data from within the survey, qualitative data was intended to be collected though a focus group discussion. Eight of the ten participants that had completed the survey volunteered to participate in the focus group. An anonymous online poll was sent to these eight participants to find a date and time that was compatible with their schedules. Two dates were determined with the hope that there would be three to five participants in each group. Despite these efforts, the majority of participants were unable to attend the focus groups, due to unforeseen circumstances. Only one participant attended the first focus group and two, a husband and wife, attended the second. I therefore recognised that gathering a group of participants for an additional focus group would prove to be difficult, and instead reached out to participants a second time to determine if any were interested in meeting individually. This led to two more interviews, one with a mother and one with a mother and father together.

Focus groups were first chosen as the method to collect qualitative data as I aspired to engage a small group of participants and encourage them to interact with

each other and generate meaningful discussion, while sharing their perceptions with one another and myself. However, conducting interviews singly or with parent couples provided participants with increased time to share their perceptions without the interruption of others' thoughts. Additionally, participants may have also felt more at ease or more willing to share their perspectives without worrying of others' opinions, providing an in-depth discussion on their FQOL. Focus groups were first additionally chosen because I anticipated that as the facilitator, I could support participants to share their ideas and encourage them to draw upon each other's responses and make room for the participants to shape the discussion (Morgan, 1997). This approach contrasts with individual interviewing in that there is more facilitator involvement during such interviews. During one-on-one interviews the interviewer has more involvement and often asks supplementary questions, encouraging participants to provide more in-depth answers, thereby shaping the direction of the interview somewhat more than when there is group involvement. However, individual interviews do provide the opportunity for flexibility as with each new interview, questions can be added or re-ordered using information gained from the previous interviews (Greenbaum, 2000). In preparation for this a guide for the focus group discussion was created with set topics and questions that built upon the surveys' results (see Appendix F). However, with each interview I was able to slightly augment and re-organize the guide in order to create a better flow of questions. This helped draw out participants' thoughts, while keeping them aligned with the focus of the interview, and allowed

them the opportunity to reflect on their families' experiences and provide

thoughtful and detailed accounts of their FQOL.

The interviews were audio taped by two recording devices to ensure that

data was fully captured for later analysis. Interviews ranged from 25 minutes to 70

minutes. Before the interviews began, participants were asked to sign a continuing

consent form (see Appendix G) to confirm their ongoing consent and participation

in the study. Participants were given the option of not answering questions if they

felt uncomfortable and were informed that they would be given the opportunity to

read over the written transcripts of their interviews at a later date. Four interview

transcripts that were emailed to interviewees for the purpose of transcript

feedback. One was sent back with changes and corrections.

Data from the interviews were analyzed by thematic analysis. Thematic

analysis is a process of organizing and interpreting qualitative data to find patterns

and create a narrative understanding of participants' described experiences (Crowe,

Inder & Porter, 2015). It is commonly used to identify data that relates to already

classified patterns. Thus, when beginning the analysis, the researcher usually has a

list of known or anticipated themes to be found in the data (Ayres, 2008). Thematic

analysis is a theoretically flexible approach that surpasses simply counting frequent

words or phrases, and focuses on exploring the "connections between explicit

statements and implicit meaning" (Attride–Stirling, 2001, p. 387.) Crowe *et al.*

(2015) list the analytics process as follows: 1) Become familiar with the data; 2)

generate initial codes that relate to study's research questions; 3) search for basic

themes and create cluster codes of connected ideas; 4) define or name themes in

relation to all data found; 5) reference themes by illustrating quotes within the transcript that capture the essence of the themes; 6) examine and interpret themes all together and develop a narrative of the results, and; 7) synthesize themes together focusing on what the findings mean and what factors impacted the findings (p. 618). It is during this last stage that Aronson (1995) states researchers should build valid arguments for theme choices and interweave the study's findings with other published data and literature. Following the steps provided by Crowe *et al.* (2015) this study's themes were anticipated from the results of the preceding FQOL survey and nine life domains. After interviews were transcribed and sent to participants for transcript feedback, I thoroughly read transcripts as well as participants qualitative responses from the survey keeping the nine life domains and overall research questions in mind. After generating multiple codes and organizing them in separate themes, the themes were named in relation to the nine life domains. Following this, key quotes were pulled from the qualitative survey data and interview data and included in the written narrative to illustrate the results found.

        Ethical Considerations. This study received approval from the University of Victoria's Human Research Ethics Board. In order to retain confidentiality, no names of participating organizations or participants were used and each participant was given as pseudonym such as participant from family one or family three. If participants mentioned their or any other family member's name within the interviews, a pseudonym was given within the written transcript to ensure confidentiality. Participants were made aware of their right to withdraw from the

study at any time without any consequences or needing any explanations.

Participants were notified that they could remove their data from the survey results

if they decided to withdraw but could not remove their data from the focus group

results, as individual data from the focus group was impossible to remove. That

being said, as interviews were used in lieu of focus groups participants were able to

withdraw their data if required. Additionally, interview participants were sent a

copy of the transcript of their interview so they could review it and make any

changes or fix any errors that they felt necessary.

In keeping with the University's Human Ethics Board, participants were

made aware of the potential risks of participating in the study, such as experiencing

emotional or physiological responses when reflecting upon their family and family

quality of life. It was essential to me that participants felt comfortable sharing their

thoughts and perspectives. Therefore, to mitigate the study's risks participants were

provided with the contact information of a clinical counsellor who had experience

working with families and individuals with disabilities. Participants were notified

that they could contact the counsellor for a counselling consultation if they felt

overwhelmed at any time during the study.

Chapter Four: Findings and Discussion

Creswell (2014), referring to the discussion and interpretation section of a

study using an explanatory sequential mixed methods design, suggests that

researchers should report quantitative findings first, qualitative findings second and

then finish with a discussion of how the qualitative findings help explain the

quantitative results. However, due to the length of the survey and amount of

interview data gathered in this study on each of the nine life domains, the report on

the quantitative and the qualitative data were merged in order to avoid repetition

and provide more clarity. Thus the findings of this study are organized as follows: In

the first section the quantitative results collected from the surveys are presented in

Table 2 to provide an outline of participants' perceptions of their FQOL and nine life

domains with regard to 1) how **important** each domain is; 2) how many

opportunities are available in their area to develop or engage in each domain; 3)

how much effort or **initiative** they put into developing or maintaining each domain

and; 4) how **satisfied** they are with each domain. As previously indicated due to the

small sample size quantitative results shown indicate the numerical not statistical

difference between participants' responses.

This is followed by a second section that provides an in-depth description

and discussion of both the quantitative and qualitative findings regarding each of

the nine life domains and examines the agreement or otherwise between the

participants' survey and interview responses, to further explore and gain a deeper

understanding of their perceptions. Three types of data are presented in this

section: the survey results, illustrative comments from the survey, and interview

responses. It should be noted that four of the ten families surveyed (family participants number three, five, seven and nine), participated in the interviews and are therefore listed under the same numbered pseudonym. Families three and nine included two parent participants in the interview who made clear they had shared beliefs and confirmed each other's perspectives, as they frequently finished each other's thoughts or one parent's comments fed into the other's, building on each other's statements. Therefore, both mothers' and fathers' ideas and comments from these interviews are collectively presented as one response for example, 'participant from family three' and 'participant from family nine'.

In the third section I compare the quantitative findings of my study with the findings of a FQOL study on families with children with IDD conducted by R. Brown *et al.* (2006). This study was chosen for the comparison as it uses similar measures, and emphasizes some of the key similarities and differences between the FQOL of families during different life stages.

FQOL Dimensions and Domains

Table 2 *Mean and range scores for Importance, Opportunities, Initiative and Satisfaction dimensions of nine domains of FQOL (N=10)*

Domain of FQOL	Importance		Opportunities		Initiative		Satisfaction	
	Mean	Range	Mean	Range	Mean	Range	Mean	Range
Health of Family	4.40	5-3	3.60	4-1	3.60	5-2	3.30	4-2
Financial Wellbeing	4.46	5-4	3.20	4-1	3.80	5-3	3.40	4-1
Family Relationships	4.70	5-4	3.00	4-2	3.40	5-1	3.35	5-1
Support from Others	4.20	5-2	2.15	4-1	2.70	5-1	2.60	4-1
Support from Services	4.80	5-4	3.40	5-2	4.10	5-2	3.00	4-1
Influence of Values	3.80	5-1	2.90	5-1	3.00	5-1	3.20	4-1
Careers and Career Prep	4.25	5-4	2.44	4-1	2.80	5-1	3.37	5-2
Leisure and Recreation	4.20	5-3	3.60	5-1	3.40	5-1	3.60	5-2
Community Interaction	4.30	5-4	3.70	5-2	3.40	5-2	3.30	5-2

Table 2 highlights the mean and range scores for each measured dimension in each of the nine life domains. All items are scored on a five point likert scale ranging from one to five where higher scores indicate higher levels. Range scores illustrate how varied participants' ratings were, showing both the highest responses and the lowest responses that participants reported for each dimension in the nine life domains. For example, Table 2 illustrates how participants' responses were quite similar with regard to the **importance** of the nine life domains within their family's quality of life (rated between three and five) except for influence of values and support from others. The table also shows varied participants' responses were with regard to the **opportunities** available to them and the amount of effort or **initiative** they made in obtaining or engaging in each specific domain. For example,

three participants reported that their family members made 'a great deal' of effort to obtain the disability related services they need and six participants reported they made 'quite a bit' of effort while one participant reported they made 'hardly any effort at all'. Similarly, with regard to **satisfaction**, Table 2 also shows the slight variation in participants' scores in how satisfied they are overall with each life domain.

As Table 2 shows, participants view all nine life domains as important to their FQOL but do see some of these as more important than others: Support from services and family relationships were given the highest average scores, illustrating the high importance participants place these life domains. In comparison, influence of values appears to be the least important life domain overall, because although it was important to some participants, other participants indicated with their ratings and comments that they did not find it to be a significant aspect to their quality of life. This is further discussed in the influence of values section.

In general, participants indicated that there were numerous opportunities for their family to engage in three domains: community interactions, accessing services for their families' health needs and leisure and recreation. At the same time, participants reported having very few opportunities for their family members to pursue careers and career preparation, develop or strengthen their values (such as personal, spiritual or religious) and even less opportunity to receive support from others.

With regard to the amount of initiative or effort made to develop, maintain or pursue the nine life domains, participants indicated they made the most effort to

improve the support they received from services and their financial wellbeing, and to maintain or improve the health of their family. Participants also reported making the least amount of effort when it came to receiving support from others, developing or preparing for their careers and developing or strengthening their spiritual, religious or cultural values.

As can also be seen in Table 2, overall satisfaction scores were low for all domains, as each mean score was below the rating of four or 'satisfied'. However, leisure and recreation and financial wellbeing were the two areas where participants reported the most satisfaction. Support from services has a very low overall satisfaction score, although participants reported this area as very important for their FQOL and noted this as an area where they made the most effort to obtain the services their family needed. Similar to the mean scores in the dimensions of opportunity and initiative, support from others had the lowest score with regards to satisfaction, illustrating participants' concerns in this area. This is further discussed in the support from others section.

FQOL Quantitative and Qualitative Findings

Health of The Family. This domain speaks to the physical and mental health of each family member as well as their opportunities to access health care facilities and therapies. Survey questions required participants to consider the overall health of each member of their family, as the health concerns impacting one member are likely to impact others (See Table 3).

Table 3 *Participants' Responses on Health of Family*

How important is your family's health to your family's quality of life?	Very Important	Quite Important	Somewhat Important	A little Important	Hardly Important at all
	5	4	0	0	1
Are there opportunities in your area for your family's health needs to be met?	A Great Many	Many	Some	A Few	Hardly Any
	0	8	1	0	1
Do members of your family make efforts to maintain or improve their health, such as engaging in regular exercise, paying attention to diet?	A Great Deal	Quite a Bit	Some	A little	Hardly at all
	5	1	4	0	0
Everything considered, how satisfied are you with the health of your family?	Very Satisfied	Satisfied	Neither Satisfied or Dissatisfied	Dissatisfied	Very Dissatisfied
	0	6	1	3	0

The majority of families indicated that there were many opportunities for their families' health needs to be met where they lived and described various efforts made towards maintaining or improving their family's health. Just over half of the participants who completed the survey indicated they were satisfied with their families' health; however, additional survey comments from four participants illustrated their concerns and ongoing efforts of monitoring and care for the health of their family members' with IDD as well their own health. For example, the participant from family nine commented on the difficulty of finding continual opportunities for physical and speech therapies for their daughter noting, *"They show you what you need to do with your child [speech and occupational therapy] and then you are left being a (several) therapist(s) as well. It's an impossibility to be all".* Conversely, the participant from family six commented on the difficulties in finding opportunities for her own physical health explaining: *"As our son needs constant supervision it is almost impossible to have a regular exercise routine, for myself".*

Although comments within the survey focused mainly on the physical health of the family and on family members' efforts to seek out specific therapies and opportunities for exercise, participants in the interviews spoke more about their family's emotional and mental health. All the members of the four families that were interviewed spoke about the importance of recognizing their own self-care and taking breaks. Participants noted that they need time off in order to be healthy as their child with IDD ages as the management and supervision of their family member with IDD and the continual advocacy and fighting for funding could become very draining. The interviewee from family nine noted that many parents are too tired to continue advocating because, *"You are almost used up until you are sick… or until you are burned out".* The interviewee from family seven also expanded on how easily self-care can be pushed to the side in saying that, *"One thing I learned through this process is to look after myself as well, you get sort of self-absorbed in the process of trying to get your child all settled".* However, while it was recognised that self-care was vitally important to both their and their family's health and quality of life, the participant from family nine stated that it was at times impossible to get the necessary support to provide them with opportunities for self-care: *"As a parent you don't get days off and you know it is not recognised that, you know you need that time off to be healthy and they [government services] make it very difficult for you to receive that help".*

Having control or being able to make a plan was also noted as an important part of maintaining family mental health as a family member with IDD transitions into adulthood. Several interview participants spoke of experiencing feelings of

uncertainty, stress and overwhelming anxiety when they were unsure of what

funding would be available or what options or access their family members with

IDD had for employment, day programs, daily activities and housing as they

transitioned into adulthood. The desire to have a plan for the transitioning child and

the need to be able to make choices is illustrated by the participant from family

five's comment:

> *It is about control though and feeling you have a sense of control over your life.*
>
> *And when we talk about being out of balance as families often do, it is because*
>
> *we feel out of control in our life, so that comes with a lot of stress and anxiety.*

Qualitative comments from both the surveys and interviews on family health

showed that the needs of the entire family are not always being met as the focus is

commonly on the family member with IDD and there is not always enough support

offered to parent members for them to take advantage of opportunities present. As

the participant from family seven stated, *"your life revolves and is focused on them".*

This is echoed in the participant from family three's statement:

> *The sponge that the child takes from you and the time, just gets sucked into*
>
> *that child and you still have to do laundry, meals, go to work, drive, soccer, you*
>
> *still have to do all that and 90% of you time if you don't have the right help, it*
>
> *gets sucked into that child.*

It should be noted that the five participants who indicated their family

members with IDD had behavioural difficulties such as '*insomnia*', '*meltdowns when*

they are unable to communicate their needs', '*angry outbursts*', and '*self-injurious*

behaviours' reported lower satisfaction in the majority of the nine life domains,

including health of the family, than those who did not indicate behavioural issues. This may suggest that when there are larger behavioural issues with a family member with IDD, the overall FQOL for other family members may be lower because the individual with the disability has many needs and so draws on the family's resources to such a degree that this stands in the way of other family members need to enhance their own FQOL. Davis and Gavidia-Payne (2009) noted similar results in their study on FQOL and young children with disabilities. They found that families with children with severe behaviours shared feeling of increased stress and lower levels of general wellbeing within their family. The same authors suggested that families with children with severe behaviours need varying levels of support and assistance to match their unique needs. As such, this appears to be an area where further study is needed in order to determine how families are affected and what additional supports families may need when their family members with IDD are transitioning into adulthood and exhibit severe behavioural problems.

Financial Wellbeing. This domain examined how families earn their money, determine their financial needs and view their overall financial situation including their perspective on if they have the means to pay for what the family needs or in some cases what the family wants. Table 4 outlines participants' survey responses.

Table 4 *Participants' Responses on Financial Wellbeing*

How important is financial well-being to your family's quality of life?	Very Important	Quite Important	Somewhat Important	A little Important	Hardly Important at all
	6	4	0	0	0
Are there opportunities for members of your family to earn enough money to do the things you family wants?	A Great Many	Many	Some	A Few	Hardly Any
	0	5	3	1	1
Do members of your family make efforts to maintain or improve the financial situation of your family?	A Great Deal	Quite a Bit	Some	A little	Hardly at all
	1	6	3	0	0
All things considered, how satisfied are you with the financial well-being of your family?	Very Satisfied	Satisfied	Neither Satisfied or Dissatisfied	Dissatisfied	Very Dissatisfied
	0	7	1	1	1

Within this domain, the majority of participants rated their initiative and satisfaction levels as high, and half of the participants indicated there were many opportunities for their family members of their family to earn money. However, the five participants that provided additional comments on this domain described the financial challenges they faced, including the lack of personal finances and the amount of government funding available. The participant from family one stated: "*This is an extremely complicated legal/fiscal situation that remains in a 'limbo' that is unresolved, causing enormous stress to me as the primary caregiver and financial provider".* Two parents commented on the difficult choices they or their spouses have had to make with regard to their financial situation, such as leaving a job and living on one income or working extended hours. The participant from family nine commented: *"[I] had to give up my career as a health care worker to care for my daughter. It is extremely difficult to make ends meet with one income".* While the participant from family six stated: *"My husband works weekends and evenings to help financially".*

The responses that were provided during the interviews describe many challenges surrounding finances and funding and the families many efforts to advocate and fight for funding, which further illustrates survey participants' comments. All participants of the four interviewed families spoke of their careers and family members' current employment, which will be further discussed in the careers and career preparation domain. Two interviewees indicated that they were doing well with their personal finances due to at least one spouse having a well-paid job, but expressed frustration with the relative financial disadvantages with having a family member with disabilities. For example, the participant from family three noted how the rising costs of providing support and services for their child with IDD affected other aspects of their family life:

We ended up initially paying for support ourselves. Right at the beginning. No one is going to reimburse us for that but I was making a decent wage, you [his wife] were still working part time...Of course trickles down, if I spend $5000 on hiring staff to care for that child, that is $5000 dollars that I can't spend on my other children or put towards mortgage or the new car or savings so, the domino effect to that is that your mortgage doesn't get paid off when you want to, retirement may not happen when you had planned and I mean while the fall of dominos is significant and we are fortunate to say that I have a good job and she gets paid very well when she works and I get a pension plan with the military, I get a good plan and I am working on a second pension right now as well as working for the public service so it will all work out in the end, but not everyone is as fortunate as I am.

Family three's participant's comment highlights that although they are relatively well positioned to care for their family members with disabilities and are able to pay for additional costs themselves when funding is not provided, there are many families who find the extra costs associated with having a family member with disabilities to be an enormous financial restraint. The participants noted that it has been necessary to fight for every bit of funding they have received. For example, the member from family nine stated you have to, "*keep going up to someone higher on the food chain until you get results,*" indicating that there are many barriers to receiving the necessary and entitled funding from government services to pay or assist in paying for respite, in home support, consultant services, day programs as well as unforeseen extra costs. As the participant from family three shared:

We will both call the same organization at different times. It drives them up the wall and I won't tell them I have spoken to her. I will play totally naïve and stupid, 'Oh, I didn't know my wife called, but I do know my rights' and so you play the game… The only reason we got the hours we did for outreach was because we complained. We followed the complaint process and you have to play the game otherwise you don't get anything.

Interviewees from families three, five, seven and nine also all commented on their experience of the assessment and eligibility process for funding their families when their child transitioned into adulthood. The participant from family five provided a detailed account of their family's experience:

I think a part of it was you did all this planning and assessment for eligibility which was [deep breath] okay, and then and you start doing this planning

process which you, which seems to go pretty well. You talk about your dreams and your vision and Xavier is central to that and he gets to decide what's important and then of course you get determined eligible and you are eligible for so many hours a week of services but then when it comes right down to it you find out that you don't get those because there is a request for services list. Right. So, there isn't enough money.

The participant from family nine also shared their experiences with receiving government funding as their child moved into adulthood:

Our daughter is a level four of level five, five being the worst and we have had to put in complaints for every increment of service she has got because she would have nothing otherwise. Being a level four, so you can imagine the three, two and one are getting even less or worse.

Throughout their interview, the participant from family nine repeatedly commented on their family's constant fight for funding and services indicating that this was a very pertinent topic for their family.

We had to get to the point where we had to fight for funding… we basically had to say 'you are going to have to take our daughter, if you aren't going to give us a day program'… so you almost have to get to that point, which I would never do to her, but they make you do that which is… to even say those words is disheartening… it's really disheartening.

Families' comments highlight the emotional and financial struggle that is an integral part of their child's transition from adolescence to adulthood and the increasing stress that occurs while they wait for others to determine their child's

eligibility for funding and services. This is consistent with parents' perspectives in Davies and Beamish's (2009) study. The authors found that lack of government funding was a specific concern for parents and was tied with lack of options and activities for the families as they tried to adjust to their family members' transition into adulthood and out of school. While survey results indicate that participants have higher satisfaction in their financial wellbeing than other life domains, their lower scores on the opportunities available to them in this domain and their survey and interview comments speak to the lack of opportunities, funding options and resources that these families feel are available for their family members.

Family Relationships. When reporting on family relationships, participants were requested to think about the tone or general feeling that was present between family members. It was noted that some individual members may get along better with certain family members but stressed the importance of thinking about the relationship of the family as a whole. Table 5 summarizes the participants' assessments.

Table 5 *Participants' Responses on Family Relationships*

How important are your family relationships to your family's quality of life?	Very Important	Quite Important	Somewhat Important	A little Important	Hardly Important at all
	7	3	0	0	0
Are there opportunities for your family to maintain or enhance good relationships with each other?	A Great Many	Many	Some	A Few	Hardly Any
	0	3	4	3	0
Do members of your family make efforts to keep good relationships within you family?	A Great Deal	Quite a Bit	Some	A little	Hardly at all
	2	3	3	1	1
All things considered, how satisfied are you with the relationships within your family?	Very Satisfied	Satisfied	Neither Satisfied or Dissatisfied	Dissatisfied	Very Dissatisfied
	1	4	3	1	1

Compared to other domains, the results in Table 5 show that participants feel there are fewer opportunities in this area of their lives, although it is one of the domains where they report making a higher initiative or amount of effort when it comes to creating or maintaining relationships with family members. Very few participants added comments for this life domain, however two mentioned damaged or estranged relationships with their extended family members and the participant from family ten noted that a recent move left the family *"feel[ing] less connected to family supports"*. The difficulty in maintaining family relationships and feeling connected to extended family was consistently illustrated through the few comments made, which may reflect why scores assigned to the questions about opportunities were low.

Interview responses focused on family relationships within participants' immediate family. It was noted that disability affects all family members, is tough on family relationships and as the participant from family nine shared makes it *"hard to find quality time".* Participants' comments supported and amplified the survey's results as all the interview participants indicated that their relationships with their family members were essentially important to their FQOL, that it was a struggle to find opportunities to maintain or work on these relationships and that they took many initiatives to develop these relationships such as through engaging in shared activities with all members or small groups. Ideal family quality of life was depicted as having time for everyone together as well as specific times with separate family members, however the participant from family nine expressed difficultly in having those opportunities: *"Sometimes at dinner we can't talk…she [daughter with IDD]*

gets upset if she perceives that we are having an argument… or talking about a frustration…. and when you are frustrated sometimes it is useful to just get it out… so all you can do is angry text". The participant from family five reflected upon the balance in their family and how important it was that everyone was active with their own activities and endeavours but had the ability to feel comfortable in their home and take breaks together: *"We get busy sometimes so for us vacations are actually a really important aspect of quality of life".*

Participants from families three and nine commented on the stress that having a child with disabilities puts on a marriage and how much each spouse relies on the other, using a tag team system, as well as the difficulties that arise when one spouse is away for work. For example, the interviewee from family three stated:

We literally had times when one would come in and one would go out because we actually knew, like I knew I had hit my limit at the end of the day and I am just counting, 'they are all set up at the table, the meals are out, they are all secure; I am out' and I will just go for a walk and those are the days that he was there so you can just imagine when he wasn't.

Coming for a single parent family, the participant from family seven acknowledged the challenges of being a single parent and getting to a *"place of good quality of life"*, but stressed that the biggest challenge was finding and accessing *"services and activities to engage both or either me or my daughter"* as well as *"finding the time to do stuff".*

Participants indicated that they valued the support from their internal or immediate family members. Overall participants' accounts reflected how important

their relationships with their internal family members are and how they relish the opportunities to spend time together as a family unit as well as with individual members. The interviewees suggested that they rely on their immediate family members such as their spouses or their children for emotional and practical support through means of respite, tag team parenting or positive interactions and experiences with one another. This may suggest that the participants rely on their immediate family relationships because they are not receiving the support they want and need from their extended family members, friends or neighbors. As young family members in a FQOL study by Brown *et al.* (2003) noted, they expected "family relations [to] be strained in the near future" (p. 214). Results from my study indicate that families with an individual with IDD who is transitioning into adulthood maintain good relationships with their immediate family but do struggle to maintain the relationships with their extended family members, which corresponds with participants concerns in the study by Brown *et al.* (2003).

Support from Other People. Within this domain, participants were asked to reflect upon support from relatives, neighbours, friends and other natural supports; results are illustrated in Table 6.

Table 6 *Participants' Responses on Support from Other People*

How important to your family's quality of life is the practical and emotional support you get from other people?	Very Important	Quite Important	Somewhat Important	A little Important	Hardly Important at all
	5	3	1	1	0
Are there opportunities to receive practical and emotional support from other people excluding service providers, should your family need it?	A Great Many	Many	Some	A Few	Hardly Any
	0	2	2	2	5
Do members of your family make efforts to get practical and emotional support from other people, excluding service providers?	A Great Deal	Quite a Bit	Some	A little	Hardly at all
	1	1	4	2	2
All things considered, how satisfied are you with the practical and emotional your family gets from other people, excluding service providers?	Very Satisfied	Satisfied	Neither Satisfied or Dissatisfied	Dissatisfied	Very Dissatisfied
	0	2	4	2	2

As previously noted, support from other people yielded the lowest scores in three of the four dimensions including opportunities, initiative and satisfaction yet is was regarded by eight of the participants as important (5) or quite important (4). This finding is consistent with FQOL findings from Werner *et al.* (2009) where support from others was the lowest domains in almost all dimensions. Participants' low scores from this current study were accompanied by their comments on the lack of support available and the difficulty of obtaining and maintaining relationships with extended family members and friends, mirroring participants' comments in the domain of family relationships. The participant from family nine spoke about other people's disinterest in their family's challenges: *"People get tired of hearing about issues that you're advocating for as it seems to be ongoing continuous problems. It's like walking in someone else's shoes - sometimes it's hard to have empathy".* Within this section this participant also noted the difficultly in receiving support from family members: *"We have no family members who are able to support*

us. Adult siblings are all in need of support or are unable to help. All outside care is paid respite". The lack of support in this domain was also commented upon by the participant from family eight who noted how the proximity of family members and friends and how physically close they lived contributed to the amount of support they felt was available: *"We have no immediate family in town and most of our friends are not forthcoming with support".* Two survey participants who gave high rating for both opportunities and initiative in this domain were correspondingly the only two who indicated that they were 'satisfied' with the support they received from other people. A supplementary comment from the participant from family one suggests how important the support their family receives from others is to their FQOL: *"Extended connections to friends and associates have become critically important to our overall wellbeing".*

When given the opportunity to further delve into discussion on the support they received from others, all the family members who were interviewed shared more positive perceptions about the support they were receiving. Participants said that they found the most valuable support came from connections and relationships with other families that have children or adult members with disabilities who had gone through similar experiences. These families connected through support groups, at their family member's daily activities, on Facebook, or when they gathered together at events. Participants noted that that in times of isolation, they felt strengthened by other parents who understood their lifestyle, and that they had maintained relationships with parents and families they met when their child was first diagnosed. One of the members from family nine shared:

[We] find if someone else like outside the family understands autism that is a

help for us... We have a lot of family that don't understand our daughter, so they

just basically back out of your life because they don't know what else to do... If

there is understanding you have a better more positive sort of feedback with

people.

Other families were also noted as good sources of information as the participant

from family seven explained:

Sometimes they will know things I don't, you often don't get services or ideas

from the government or the agencies that are supposed to help you out. So, it is

usually just maintaining those connections and relationships [with families] I

find really critical.

Interviewees emphasized how important it was for families moving into the

transition to reach out and take the initiative to find groups that fit their needs or

other families to connect with for support or information. A participant from family

three suggested: *"Try and connect with other families. That has been hugely*

valuable... try and connect in and say 'Hey how does that work for you'?"

Interview responses highlighted how these families strive for connection and

support when they cannot find it elsewhere as interview participants emphasized

how much they valued the support they received from other families with individual

members with IDD and how crucial those relationships were to them. Interview

responses did not oppose survey ratings, as support from others was indicated in

the interviews as a very important life domain that participants were not fully

satisfied with. This was similar to what the numbers in the survey indicated,

however interviewees responses did appear to indicate that participants and their families put great effort into seeking out opportunities and engaging with others families with children with IDD both providing and receiving support which was not illustrated within the survey ratings or commented upon within the survey comment section.

Overall participants' interview comments in conjunction with the low survey ratings and written responses indicate that the families find the lack of support from others such as family members, friends and neighbors, to be one of the principle challenges when their child with IDD transitions into adulthood, indicating that there is considerable space for enhancement in this life area. Results from the survey support those found in other recent FQOL studies, such as in Rillotta *et al.* (2012) where a relatively large percentage of the 42 surveyed participants indicated that they were not satisfied with the practical and emotional support they received from others and in R. Brown *et al.* (2006) where results showed low levels of respondent satisfaction in both the Down syndrome and autism participant groups. Given the range of age groups that have reported a lack of support from others (R. Brown *et al.* (2006) focused on families with members with disabilities aged 3-13; Rillotta *et al,* (2012) focused on families with members with disabilities aged 2-46; my study focused on families with members with IDD aged 18-30) it appears that experiencing a lack of support from others is a life-long challenge for families with members with IDD.

Support from Disability Related Services. Questions regarding *support from services* asked participants to think about any support their family received from

disability related services while their child was transitioning into adulthood.

Participants' responses to these questions are summarized in Table 7.

Table 7 *Participants' Responses on Support from Disability Related Services*

How important to your family's quality of life is support from intellectual and developmental disability related services?	Very Important	Quite Important	Somewhat Important	A little Important	Hardly Important at all
	8	2	0	0	0
Are there opportunities in your area to receive the intellectual and developmental related services your family needs?	A Great Many	Many	Some	A Few	Hardly Any
	1	3	5	1	0
Do members of your family make efforts to obtain the disability related services they need?	A Great Deal	Quite a Bit	Some	A little	Hardly at all
	3	6	0	1	0
All things considered, how satisfied are you with the disability related services your family receives?	Very Satisfied	Satisfied	Neither Satisfied or Dissatisfied	Dissatisfied	Very Dissatisfied
	0	4	3	2	1

Table 7 shows the sparse number of opportunities and low level of satisfaction

and support most participants felt they received from disability related services as

well as the high level of initiative or effort they put towards accessing necessary

services. Participants indicated that they put the highest level of initiative towards

attaining support from disability related services. Many survey participants

commented that there were many programs their family members with IDD

attended, such as local day and community programs available, but three

participants emphasized that they had difficulties getting into them due to limited

government funding. The participant from family three noted: *"There are many*

service providers available but accessing those services is limited to government

funding available. [We're] dissatisfied with the process of getting into services from

CLBC". The participant from family one commented on the great efforts of advocacy

she put forth for her family: *I have spent nearly 20 years in accessing all levels of*

support and services (medically, educational, fiscal, legal, and community inclusion)

for my loved one. I am in constant advocacy mode". This comment sheds light on the

high level of initiative participants indicated they take when it comes to accessing

services for their families. In response to the low level of support and opportunities

from disability related services their family received, the participant from family

five spoke of the creative ways their family obtained the services and government

funding they needed: *"We are part of a family governed group using individualized*

funding so we design our own services".

  As previously indicated within the domain of financial wellbeing and in the

survey comments above, lack of funding was a significant topic for family

participants with individuals with IDD who were transitioning into adulthood. In

addition to negatively affecting their financial quality of life, interview participants

cited lack of funding as a leading cause of their dissatisfaction with government

funded services such as Community Living BC (CLBC)[2]. The participant from family

nine shared that as children age into adult services, they lose significant funding and

service opportunities such as autism funding and VIHA services, as the adult

disability services are all under the umbrella of CLBC: "*There is huge funding dollars*

given to children and families and when they become adults it is almost like 'well they

don't need it any more'. So, they don't have that".

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[2] Community Living BC (CLBC) is a provincial crown agency supported by the BC
Ministry of Social Development that provides funding for supports and services for
eligible individuals with IDD who are over the age of 19 and their families. Funding
can be provided to families directly or accessed through service providers and
agencies.

Coupled with the lack of an adequate provision of funding, interview participants found that their family members' transition into adulthood services was a period filled with *"a lot of unknowns"* as they worked through a new confusing and cumbersome system as stated by the participant from family five:

> *Those unknowns were primarily coming from the systems that were supposed to be serving us, so that just added to the anxiety and stress and feeling of lack of control, when you don't know if you are going to get services and so you can't plan for them properly.*

The family member from family seven echoed these feelings of uncertainty when their family member with IDD was moving into adulthood and commented on their need for a clearer process.

> *It would have been nice to have been given more direction, because I have just had to fumble around...I prefer it not to be so much trial and error. It is your kid after all. I would rather it not be but we manage.*

Interviewees expressed their unhappiness with what they called a *"slow"*, *"convoluted"*, and *"archaic"* system where they were *"expected to already know everything"* or *"figure it all out".* Their comments demonstrate the high level of responsibility that has been placed on them as parents to determine their own resources, create their own proposals, ideas or designs for care as well as figure out all that their family are entitled to and fight to receive it. Participants discontent with the government services for individuals with IDD is illustrated by the participant from family nine's comment: *"It feels like CLBC is there but to some degree it just feels like they are a barrier or a wall, not a support".*

While their frustration with government systems and disabilities services was a reoccurring and central theme within all the interview participants' data, participants also commented on the positive contributions their local disability services and programs[3] provided for their family. Local service providers were noted as being more flexible and considerate, and providing the participants' families with individual understanding and tailoring programs specifically for their family members with IDD. The participant from family seven commented on how local services have provided their family with positive experiences such as coaching services and day programs where *"they always ask us for feedback and involve us where we need to be and if we see things".* Two families also spoke highly of host agencies. For example, the participant from family five commented that their host agency *"act[s] as a resource and support"* and provides their family with opportunities for *"true collaborative problem-solving discussions together".* Their comments illustrated, that while still rated low in satisfaction in comparison to other life domains, there is some level of satisfaction with disability related services, at least where local service providers offer more flexible, individualized and tailored care for their family members with IDD, while also providing opportunities for their family's input and decision making.

Interview comments further illustrate survey results and explicitly demonstrate how participants experience a general disconnect between

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[3] Local service and program providers in this study are regional for profit, non-for profit, or charity organizations that provide day programs, community support or outreach, etc., to individuals with IDD and their families. These programs are mainly provided to individuals with IDD who are eligible for services through CLBC.

government ministries and service providers, and how their families' continual fight to access funding and programs leaves them with unnecessary stress and anxiety, therefore contributing negatively to their FQOL. Parents' perspectives on the lack of support they receive when moving into adult disability services resemble comments made in a previous transition study by Rapanaro *et al.* (2007). Parents in Rapanaro and colleagues' study commented on the sudden withdrawal of services and funding when a child transitioned into adulthood and the sorrow felt when anticipated funding was not provided. Similarly, mothers in the study conducted by Dyke *et al.* (2013), shared their experiences of distress while waiting for funding to be secured and their continued difficulty in obtaining funding. One mother's comment from Dyke and colleague's (2013) study mirrors comments made by participants in my study. As Dyke *et al.*'s (2013) participant stated, "you've got to stand there and because they take the worst cases first, so you've basically got to stand there and say like 'I'm a waste of space as a mother, I can't cope anymore' ... to make it really, really, bad so that they'll give you the funding" (p. 154).

As illustrated above, interviewees' comments from my study highlight how the repeated disappointments and struggles during their child's transition into adulthood affect various domains of their entire family's QOL where family members needs are not being met, including but not limited to their financial wellbeing, their careers and career planning, the health of their family, and their family relationships. Conversely, all interviewees also noted that when they are supported with accessible services and available funding to attain the supports they need, and have options and choices that fit their lifestyle their families' FQOL raises.

Within the four interviews, parents made suggestions for how disability services and systems could be more beneficial to their own and other families FQOL as they move into the transition period with their child with IDD. Parents suggested that 1) streamlining the application process to ease access to support services; 2) creating more complimentary and consistent services in one place; 3) making direct funding available similar to the autism funding they received prior to their child's transition into adulthood; 4) creating a legislative initiative around transiting youth, anticipating those who are coming up in the system and, 5) providing families with knowledgeable staff who can help them navigate the system such as the social workers they had during their time with child and family services. Within the interviews, participants also provided many of their own strategies for manoeuvring through the disability system more successfully. All four interview participants stated that they believed families with children with IDD would benefit from starting the transition process early, and suggested that parents prepare for the transition by 1) knowing what they want, thinking about what is important to their family and developing a transition plan; 2) preparing themselves for "let downs" along the way and having some alternative plans if possible; and 3) following the complaint process, continue asking questions and being persistent when they are not receiving the necessary support.

Influence of Values. In the survey, the section on the influence of values asked participants to consider what their values were and what guided these values. It was indicated that values may derive from personal codes of conduct; spiritual beliefs, religions or cultural backgrounds and participants were asked to think about how

their FQOL was affected by these values. Participants' responses are summarized in

Table 8.

Table 8 *Participants' Responses on Influence of Values*

How important to your family's quality of life are personal, spiritual, religious, and/or cultural values?	Very Important	Quite Important	Somewhat Important	A little Important	Hardly Important at all
	4	3	1	1	1
Are there opportunities for members of your family to develop and hold personal, spiritual, religious and/or cultural values that can contribute to your family's quality of life?	A Great Many	Many	Some	A Few	Hardly Any
	1	3	3	0	3
Do members of your family make efforts to maintain or strengthen personal, spiritual, religious and/or cultural values?	A Great Deal	Quite a Bit	Some	A little	Hardly at all
	1	3	3	1	2
How satisfied are you with the degree to which personal, spiritual, religious and/or cultural values contribute to your family's quality of life?	Very Satisfied	Satisfied	Neither Satisfied or Dissatisfied	Dissatisfied	Very Dissatisfied
	0	5	3	1	1

Participants' scores on the influence of values varied across each of the four

dimensions. Influence of values appears to be a high priority for some participants

and as a low priority for others. Comments were similarly varied, as the participant

from family eight noted: *"Religious values [and] pursuits [are] not an emphasis for*

*this family", w*hile the participant from family seven wrote: *"[Values are] incredibility*

important for a calm household". The participant from family six's comment

indicated that their values combined with support from others, positively affecting

their FQOL: *"We have a church family that provides encouragement and friendship".*

During the interviews, participants made little note of the influence of values

domain and offered scarcely any comments on codes of conduct, religion,

spirituality, culture or how their personal values contributed to their FQOL. Only the

participant from family five commented:

I couldn't care less about faith, right so it doesn't matter to me if I don't go to church, you know to me when I think of quality of life it is so much about values and important and priorities and family and the reality of how much is actually happening and how much is matching back to those priorities.

Influence of values received the lowest score in terms of importance, with a mean score below a rating of four or 'quite important' while all other domains received a score of four or higher in this dimension. However this domain attained mid-range ratings in the dimensions of opportunity, initiative and satisfaction in relation to other domains. These results contrast with some previous FQOL studies, (Ajuwon and Brown, 2012; Rillotta *et al.,* 2012) where participants rated influence of values with high importance and high satisfaction. However, they are similar to findings in the study by Bertelli *et al.* (2011) who found that while participants' cultural and spiritual beliefs were reported as an important support for families, the domain had a low satisfaction score thus suggesting that participants were not having their expectations met in this area of life. In this current study, influence of values may have become a lower priority for families specifically during the transition stage as other life domains such as support from services, financial wellbeing, community interaction or other life domains begin to take up a larger portion of their time and focus. Alternatively, given that the other studies that offer us points of reference on the influence of values domain were conducted in different countries, (Ajuwon and Brown (2012) in Nigeria; Bertelli *et al.,* (2011) in Italy and; Rillotta *et al.,* (2012) in Australia) participants in these studies are likely to have very different sets of values or value systems, for example strong religious affiliations, that may affect

their FQOL and therefore there their survey responses. This could mean that the results in this current study may be reflective of the underlying value system of the study's location.

Careers and Preparing for Careers. The domain of *careers and preparing for careers* examined participants' perspectives on how having a family member with a disability affected the employment, careers and education of family members as a whole. In this domain, participants were given the option of responding 'does not apply to my family'. Three participants indicated on one or more of the four questions that this domain was not applicable to their family. The participant from family ten added a comment to explain: *"My son's disability level makes employment unlikely and I am retired".* Survey responses are summarized in Table 9.

Table 9 *Participants' Responses on Careers and Preparing for Careers*

How important is it to your family's quality of life, for family members to pursue or prepare for the careers they want?	Very Important	Quite Important	Somewhat Important	A little Important	Hardly Important at all	Does Not Apply to my Family
	2	6	0	0	0	2
Are there opportunities for members of your family to pursue the careers they want and attend the school they want?	A Great Many	Many	Some	A Few	Hardly Any	Does not Apply
	0	3	1	2	3	1
Do members of your family make efforts to develop their education and/or careers?	A Great Deal	Quite a Bit	Some	A little	Hardly at all	Does not Apply
	2	2	0	3	2	1
All things considered, how satisfied are you with your family's careers and ability to prepare for those careers?	Very Satisfied	Satisfied	Neither Satisfied or Dissatisfied	Dissatisfied	Very Dissatisfied	Does not Apply to my Family
	2	2	2	2	0	2

Survey participants' scores were diverse in this domain. Participant's overall scores indicate that there are very few opportunities for careers and preparing for careers and that participants and their family members take fewer steps towards

developing this life domain than in most other domains. The participant from family six commented that although she would like to engage in furthering their education, there is not the opportunity to do so: *"I would like to attend night school to upgrade my office skills, but it is not possible".* On the other hand, two participants commented positively on the different career and educational prospects available to their family members with and without IDD. For example, the participant from family one shared her ideas about future career endeavours she envisions for her child with IDD: *"I believe when my loved one has matured in a few years she will participate in creating and making a business for herself and a good friend".* While the participant from family eight commented on other family members current educational pursuits: *"Our daughter is in post-secondary education and I have workplace resources for pursuing lifelong learning".*

During the interviews, all members of the four participating families commented on their family members' jobs, careers or education. Two interviewees spoke of the jobs their family members with IDD have including owning their own small business and working as dishwasher in a casino. For example, the participant from family seven spoke about her daughter's journey towards getting a job and how it has been a very positive experience for their family:

> *Employment services have just been a dream for me. My daughter, she got coaching and has been in a paid position for almost three years now. So very cool, that has been critical for her, her self-esteem and being successful.*

Two interviewees reflected that their family members with an IDD were positively affected once they acquired a job as their self-esteem and confidence rose

with employment that provided them with opportunities for independence. These comments illustrate a much more positive view on employment opportunities for individuals with IDD than family members perceptions in two recent studies on transition. For example, in a study by Cheak-Zamore *et al.* (2015) both caregivers and youth with ASD commented negatively on the lack of employment opportunities and training that facilitated employment. Mothers in Strnadová and Evans (2013) reported on the shortage of opportunities and the limited say their children with intellectual disabilities had for educational or employment pursuits as they transitioned out of school. However, similar to participants in this current study, parents in a transition study by Jivanjee *et al.* (2009), commented on how their family members engagement with education and careers that fitted their abilities and ambitions gave them a sense of success and personal achievement and gave them opportunities to feel connected. While parents' survey responses and comments in this current study indicate that opportunities for careers and career preparation are low and do not appear to meet all of the families' needs, some families are finding employment support and training for their family members with IDD.

Although not strictly associated with careers and career preparation, all interviewees mentioned that their child with IDD has shown growth in their independence skills during the transition into adulthood, which they described as adding to their FQOL. Participants from families three and five expressed how, although difficult during the first few years of their child's transition into adulthood, their entire families' FQOL was increasing, as their children were aging and

maturing. They noted how their children's growing independence such as learning the bus system and staying overnight by themselves was a *"light at the end of the tunnel"*.

In addition to their family members' growth in careers, education and independence, parents spoke of their own careers and career choices they have made while their family members with IDD were growing up. Three members of the interview participants remarked that the mothers have had to quit their jobs or work part time in order to stay home as caregivers. The participant from family three commented on how the loss of a career negatively impacted their FQOL:

From the time our youngest was three or four, he never slept at night so we were up hours on end and I guess another negative impact is it literally pushed me into not working at all. I mean I finally, I would always try to keep part time, like even one day a week and I think that is a big one. I don't resent it, but it is a big one [negative impact] when we reflect that I have never been able to work.

This participant's comment reflects how important her career is to the family and how the loss of it negatively affects their family, not just financially, but on a personal level. Additionally, the participant from family five mentioned: "*Family quality of life, it's around the right balance of leisure, work, contribution in terms of volunteering and community involvement and opportunities for rich diversity of activities*". This participant's comment further illustrates the personal and symbiotic part a career or job can have on an individual and to the family's quality of life as it interacts and balances with other parts of their life. Many participants in this study indicated how important *career and preparing for careers* are to their FQOL and

their comments expanded on how careers, jobs or education provided opportunities for independence, enjoyment, self-esteem for all family members. As previously noted, survey responses illustrate, given the pressures of family life with a child with IDD, how few opportunities are available to families either for their children with IDD or for other family members, indicating a need for this area to be further explored and enhanced.

Leisure and Recreation. The survey questions about *leisure and recreation* aimed to examine activities that families took part in outside of their disability related services. Participants' responses are summarized in Table 10.

Table 10 *Participants' Responses on Leisure and Recreation*

How important are leisure and recreation to your family's quality of life?	Very Important	Quite Important	Somewhat Important	A little Important	Hardly Important at all
	3	6	1	0	0
Are there opportunities for your family members to engage in leisure and recreation activities?	A Great Many	Many	Some	A Few	Hardly Any
	2	4	3	0	1
Do members of your family make efforts to take part in leisure and recreation activities?	A Great Deal	Quite a Bit	Some	A little	Hardly at all
	1	4	4	0	1
All things considered, how satisfied are you with your family's leisure and recreation?	Very Satisfied	Satisfied	Neither Satisfied or Dissatisfied	Dissatisfied	Very Dissatisfied
	1	5	3	1	0

Survey results indicate that participants find that there are numerous opportunities available for their families to engage and participant in leisure and recreational activities. The majority of participants were also satisfied with their family's level of leisure and recreation and this domain was rated highest with regard to overall satisfaction scores. However, through comments, four participants indicated that although opportunities were available, there were some difficulties

and barriers to participating in leisure and recreation activities. For example, the participant from family seven noted the difficulties in finding the right activities for her daughter to participate in: *"[It] has been challenging to get physical activity incorporated into my daughter's routine, opportunities are there but…".* Similarly, the participant from family one indicated that her family's recreational life could be of higher quality: *"Our recreational life could be more fulfilling although we are both participating in a variety of activities, for example the eight-km Good Life fitness walk".* The participant from family nine commented on the availability of recreational activities but the necessary time and effort involved in obtaining them: *"We are able to participate. It is usually time and energy on paperwork, caregiving that doesn't allow for everyone's needs to be met".* The participant from family six also noted on the advocacy and effort they made with regard to their family's participation in leisure and recreational activities: *"We take out son out to as many public events as possible. He attends community activities daily".* The participant from family eight commented on how opportunities in leisure and recreation provide good experiences for the entire family: *"We are lucky enough to have water-front recreational property, which has acted as a bonding experience".* While illustrating the positive experience that leisure and recreation has on their family, this comment also suggests that family financial resources may play an important role in determining how families sustain their FQOL in leisure and recreation as well as other life domains.

During the interviews, participants acknowledged that they find that local facilities provide good opportunities for their families' leisure and recreation but

that more opportunities and options would be ideal, especially since some programs

they previously depended on are no longer available once their family member with

IDD moved into adulthood. For example, the participant from family nine stated:

> *Rebecca is someone who needs a physical program everyday so I think probably*
>
> *it is not enough because she needs more on the weekend, she needs to do all these*
>
> *things and sometimes we don't want to always… so it feels like we are failing her.*

All family members from the four interviews mentioned their efforts to create

or access leisure and recreational opportunities for each family member. For

example, when mentioning self-care, the participant from family seven commented:

"*I am pleasantly surprised by [western community] and how much there really is to do.*

I mean even the hiking, which I have recently taken up, hiking is just beautiful up

there". The participant from family five also commented upon the importance of

leisure and recreation with concern to everyone in the family participating in a

number of different activities and finding *"the right balance"* of a *"rich diversity of*

activities". The participant from family three also reflected on the importance of

ensuring their other children within their family received leisure time with their

parents and commented:

> *We would go to Boston Pizza and do the mini golf thing and go to movies with*
>
> *them [older siblings] but it wasn't with the whole family. It was just with them*
>
> *and it was a good thing for that dynamic, so there wasn't any resentment*
>
> *towards Robert.*

All interviewees spoke on the importance of spending time on their own

mental health through self-care and on maintaining family relationships through

leisure and recreational activities. They also mentioned how the rare opportunities

for these activities supported and enhanced their FQOL in other life domains.

However, lack of time to pursue these types of activities as well as day-to-day

responsibilities was indicated to have a negative impact on their FQOL. Participants

comments and concerns are consistent with previous FQOL studies such as Brown

et al. (2003) R. Brown *et al.* (2006), and Burton-Smith *et al.* (2009), where

participants indicated concerns of time constraints and the difficultly for all family

members to maintain or pursue activities of interest. These combined comments on

finding leisure and recreational activities and opportunities for all family members

raises important questions on how FQOL in this domain can be maintained and

what services could enhance support in this area.

Community Interaction. In the final domain of the survey, participants were

asked to reflect on the sense of connection their family had with people and places

in their area. Participants' responses are summarized in Table 11.

Table 11 *Participants' Responses on Community Interaction*

How important to your family's quality of life is it for members of your family to interact with people and places in your community?	Very Important	Quite Important	Somewhat Important	A little Important	Hardly Important at all
	4	5	1	0	0
Are there opportunities for members of your family to interact with people and places in your community?	A Great Many	Many	Some	A Few	Hardly Any
	2	5	1	2	0
Do members of your family make efforts to interact with people and places in your community?	A Great Deal	Quite a Bit	Some	A little	Hardly at all
	2	2	4	2	0
All things considered, how satisfied are you with your family's interaction with people and places in your community?	Very Satisfied	Satisfied	Neither Satisfied or Dissatisfied	Dissatisfied	Very Dissatisfied
	2	2	3	3	0

The majority of survey participants found many opportunities for their family to engage and interact with people and places in their communities and two participants commented on the volunteer work or community activities their family member with IDD participates in. However, a few participants commented that although there were opportunities for interactions within their community, there were many barriers to overcome; others suggested that the options available could have been more varied and desirable. For example, the participant from family three shared: *"It is more difficult for the PWD to access the opportunities. There are more barriers".* Similarly, the participant from family nine noted how there are some opportunities but more would be optimal for their family member with IDD: *"There is a disability swim and disability dance but it is somewhat segregated to persons with disabilities. [It] would be great if there was a walking/nature group on weekends where peers could socialize. Weekends are somewhat isolated. Restaurants can be unpredictable for behaviours".* Other participants from families one, six and seven commented upon their family's continual advocacy and persistence towards finding and taking part in the community. For example, the participant from family seven wrote: *"My daughter has been very diligent in getting out and participating with community as much as she can".* The participant from family one stated: *"I deliberately and intentionally participate in community engagement processes as well as community events".* Participants' comments suggest that while there are opportunities in the community available that they do pursue, they are not always their preferred choices, nor are they easy to obtain or maintain without a large amount of time or advocacy.

Participants' comments during the interviews echoed those found in the survey. Participants noted that their family members enjoyed being in the community with their peers and social groups and that they pursued many activities. The participant from family seven commented on how positive community interaction and activities was for their family:

For community interaction, she is in a social group with a bunch of people. They started it up themselves, and they get out and go to movies and interactive game cafés whatever it is and it just, the more independent she is, the more confidence [she has].

Still, it should be noted that one interviewee from family nine also expressed her family's dissatisfaction with the lack of options and access to community connections and activities.

"She definitely needs more, more opportunities, more access. I think that is the main thing. And she enjoys going with peers, like sometimes they will take her out and she will have a great time. And sometimes she is with us, she is kind of testy but I mean what 20 or so year old... wants to hang out with their parents".

Two interviewees stated that although community interaction was important, their current focus was on helping their family members with IDD develop greater independence and independent living skills as either they felt their family members with IDD were already well engaged in the community or that social and community connections came after their children with IDD developed more independence and life skills. The participant from family three explained: *"For us it is important to start*

working on the cooking, shopping and all that because… while the social component is

huge… the outreach is what he does and needs first".

Interestingly, the majority of the comments from the interviews regarding

community interaction, centered on the individual with IDD rather than the entire

family and other individual members. However, as noted by the participant from

family five, "*When he [family member with IDD] has good quality of life I feel like it*

really affects our quality of life right, as parents". This comment, along with others in

some of the previous domains, (such health of family and leisure and recreation)

indicate that these families put their focus and efforts on their family members with

IDD first and then look towards caring for their own quality of life after.

Similar to results concerning the domain of leisure and recreation, results

from this domain indicate that families need opportunities for different meaningful

activities and outlets for interests of all family members to enjoy, either individually,

as a whole family unit or with select members together. All interviewees noted that

their families' engagement with the community and involvement in activities,

including work, education and volunteer opportunities in their communities

increased their FQOL. Participants also noted that increased activities and

involvement in the community enhanced the social skills, communication,

independence, self-esteem, and self-confidence of their family member with IDD.

However, two of the participants who were interviewed expressed their need to

latch on to certain activities or programs for their family members with IDD, as

others had been lost during their family members transition into adulthood and a

few other participants commented on their wish for more variety and opportunities in this area.

These results suggest that both parents and their children with and without IDD benefit from time and activities together and apart, and illustrate how interrelated the life domains are, as successes and increased FQOL in one area such as community interaction or career and preparing for careers impacts other areas positivity. They further illustrate how critical supports such as 1) respite services; 2) funding availability and options; 3) innovative service providers that are easily accessible and timely and; 4) family resources are to the participants and their families as they offer them opportunities to participate in the activities and programs they enjoy, or do the necessary activities for family functioning. Results indicate that an increase in these services and more options for participants could be extremely beneficial to all of their family members FQOL. The results additionally suggest that families' opinions of what their needs are and what services they desire should have a larger impact on the funding and support options given. For as suggested in Burton-Smith *et al.* (2009) if individuals with disabilities are to be successfully supported by their families, who are taking on more responsibilities and caregiving roles, then it is necessary to understand the needs of other family members and take this into account when creating support strategies and services.

Study Comparison

A comparative analysis between my study and another FQOL study with similar methods was conducted. This comparison aimed to explore parallels and differences in the two studies. Therefore, results from my study were compared with results

from the study conducted by R. Brown *et al.* (2006), to determine if there was a rank order correlation between the studies satisfaction responses on the nine FQOL domains*.* R. Brown *et al.* (2006) conducted a FQOL study on families with children with IDD specifically focusing on the differences between families with children with Down syndrome and autism as well as families with children with no disabilities. This study was chosen for a comparison with my study as both studies used the FQOL-2006 survey*.* R. Brown *et al.* (2006) used an earlier version, however it only has minor differences in the domain of satisfaction. Both studies sent the survey to interested participants, asking for the completed surveys to be mailed back. Additionally, both studies followed up with interviews to gain further qualitative data. Participants in each study were asked to consider their entire family when reflecting on the FQOL domains. Furthermore, both studies were conducted in B.C. Canada collecting participants with the assistance and support of disability organizations within the chosen communities.

Results from the study conducted by R. Brown *et al.* (2006) highlighted the percentage of satisfied or very satisfied respondents, or those participants who rated a four or five in each of the nine FQOL domains. As my study had not separated scores with reference to different disabilities, percentages from both the Down syndrome and autism group in R. Brown *et al.* (2006) were recalculated as a combined sample. A Spearman's rank correlation coefficient (Rho) analysis was then used to compare both studies satisfaction percentages. A Spearman Rho shows the degree of monotonic association between two variables that are arranged in a rank order (Salkind, 2007). A Spearman correlation coefficient measures the

strength and direction of a relationship between two ranked variables. An r_s of (+1) indicates a perfect positive relationship or association, while a r_s of (-1) indicates a perfect negative relationship (Salkind, 2007).

For this study comparison, the Spearman's Rho test indicated that the two studies' percentages have a positive linear correlation (r_s = .51). Life domains including, health of family, support from services and careers and preparing for careers showed remarkably similar levels of satisfaction. In both studies parents experienced comparably higher levels of satisfaction with respect to their family health, with 60% (or 6 participants) indicating their satisfaction in my study and 64.7% reporting satisfaction in the study by R. Brown *et al.* (2006). Correspondingly few participants in both studies indicated they were satisfied with the life domains of support from services and careers or preparing for careers as only 40% (or four participants) in my study indicated they were satisfied with support from services and only 46.9% were satisfied in the study by R. Brown *et al.* (2006) and 50% (or 5 participants) in my study were satisfied with careers and preparing for careers and 47% of participants were satisfied with careers and preparing for careers in the study by R. Brown *et al.* (2006).

However, the positive linear correlation between these two studies is not statistically significant. As such, while correlated, the weakness of the relationship may be due to a number of factors. Firstly, the ages of participants and individuals with disabilities may have produced different results. The study by R. Brown *et al.* (2006) was conducted on families with young children while the present study focused on families with adolescents and young adults. Whereas in my study

parents' ages ranged from 48 to 61 and individuals with IDD ages ranged from 18-26, parent participants in the study by R. Brown *et al.* (2006) ranged from 38-45 years of age and their children's ages ranged from 2-13 years. Therefore, satisfaction with the nine life domains may differ due to the life stage the families are currently in, and the amount of relevance they assigned to certain domains. For example, within my study only 50% or five of the participants were 'satisfied' or 'very satisfied' with their family relationships while 80% in the study by R. Brown *et al.* (2006) were. Potentially, as families age, they become more disconnected from their external family members or feel the loss of support from them as they can no longer understand the continual needs of the individuals with disabilities as these family members move from adolescence to adulthood. The participant from family nine expressed this sentiment when they commented: *"(We have a) large extended family on my husband's side that couldn't be bothered with our daughter. I have one sister that is estranged".*

Additionally, in the study by R. Brown *et al.* (2006) only 38% of participants responded that they were 'satisfied' or 'very satisfied' with their financial wellbeing, while 70% or seven of the participants in my study noted they were 'satisfied' or 'very satisfied'. As participants in my study were older they may have higher salaries or more advanced positions than those in the study by R. Brown *et al.* (2006). However, as these two studies are ten years apart, it may be difficult to make comparisons with regard to expectations of financial wellbeing, as ten years ago much of the world was heading towards what became a global financial crisis. As well, although participants in this study noted satisfaction with their financial

wellbeing, those that made additional comments noted a lack of financial and funding opportunities as well as the increased amount of work necessary to make sufficient funds for the family.

The lack of a significant positive linear correlation between these two studies may be influenced in part by the relatively small sample size of my study in relation to the sample size of participant in the study by R. Brown *et al.* (2006). R. Brown *et al.* (2006) were able to obtain 51 completed surveys from a broader area in B.C. while this study was able to obtain data from only 10 completed surveys from one city in B.C. Therefore, further study on a larger sample may provide a closer positive correlation between satisfaction ratings, or the opposite may also emerge as social conditions continue to change.

Chapter Five: Implications, Limitations and Considerations

Implications

Findings from the present study have implications for future research and practice. Participants in this study identified the difficultly in maintaining or improving their relationships with extended family members, and friends and the lack of support they felt they received from them. However, interviewed families expressed that support they received from other families who had family members with IDD was crucial to their own FQOL. This disparity between participants survey results and responses and the interview responses illustrates a restriction in the definition of support from others and the need to expand this domain in order to include all the relationships that are important to families. This limitation is highlighted in Edwards' (2016) doctoral dissertation where she suggests that support from others as defined within the FQOL framework is too closely related to support from services and implies a one way relationship where families are requiring support but not contributing any support back to the relationship. Edwards (2016) suggests that support from others should be revised to "relationships outside the family" (p. 224) and include elements of "reciprocity, emotional and practical support, pathways to actions and access to information and resources" in the description of the domain (p. 225). This modification to the FQOL survey may allow participants to further explore how they receive and provide support to others and further acknowledge the positive connections and meaningful relationships they have in their lives, providing a pathway for services to further understand how to support families and build on the vital connections and

relationships that they have and need for greater FQOL. An expansion of services

and opportunities for families in transition in this area could include providing

spaces for interactions and meetings, holding events for families to gain new

information and resources as well as for all family members socialize and connect

with each other and create networks that families can rely on. This can enable

opportunities for positive reciprocal relationships for all family members and open

pathways for family members with IDD to find and maintain friendships and

support.

Similar to the domain support from others, findings from this study suggest

that the domain influence of values also appears to be restricted in its conception in

the FQOL survey. Survey responses were very varied, as some participants reported

influence of values was an area they highly valued and others reported that it was

not an important aspect of their FQOL. This may suggest a further addition or

adjustment to the survey to provide further clarification in an area that appears to

be ambiguous. Survey instructions do suggest that surveys be self-administered or

conducted through face-to-face interviews. However, it may be advantageous to

strongly recommend that the surveys be completed through face-to-face interviews

or with an assistant available to help clarify questions and encourage further

written comments to enhance results as was done in the FQOL study by R. Brown *et

al.* (2006).

Finally this study finds that as families move into the transition stage and

correspondingly into adult disability services with their family member with IDD,

they currently must rely on their own motivation, research, finances and advocacy

efforts to navigate all pieces of the new support system while trying to maintain their FQOL. This finding suggests the need that families need more consistent, easily accessible and responsive services to help them navigate the transition into adulthood. Additionally, study findings establish that these families need more opportunities and time for all members to pursue their own interests individually, with other family members or as a family unit in order to become more satisfied with their FQOL. This finding underscores the benefit of supports such as respite services, reliable and flexible day programs, employment services and collaborative host agencies all of which provide families with the opportunity to pursue their own activities, interests and connections.

Limitations

There were a number of limitations to this study. First, this was a slightly challenging population to gain access to as many disability agencies did not respond or were unable to assist in the identification of potential participants. As such the study's sample size was small and the study's statistical analysis was restricted. It would have been desirable to have a larger collection of completed surveys and interview returns as the relativity small sample of perspectives cannot be generalized to the larger population. However, this study was never expected to represent all families' perspectives on their FQOL while family members with IDD transitions into adulthood and as noted in R. Brown *et al.* (2006) "results should be reviewed with caution" (p. 242). Second, those families that chose to participate did so on a voluntary basis, so there may be differences between these families' responses and those who were not notified of the study, were not receiving services,

were unable to participate, or chose not to participate due to lack of time, energy, motivation or various other reasons. This study also recognizes that socio-economic status may play a significant role in determining how families navigate their family member's transition into adulthood. As such families from a higher socio-economic status may be over represented in this study's sample due to a self-selection bias that occurred through the recruitment process. For example, families who responded to the recruitment process are likely to be those who were reasonably financially secure or have attained funding and have the time to participate in such a study. A final limitation in this study is that only I, the primary researcher collected, transcribed and interpreted the data however, an effort was made to enhance the study's credibility through triangulation and member checking by transcript feedback confirming the accuracy and consistency of participants' accounts and perspectives.

Future Research Considerations

This study provided insight into parents' perspectives on their FQOL while their family member with IDD transitioned into adulthood. In addition to these insights this study highlighted new questions and considerations for further research. Two considerations are noted here:

This study focused on parents' or main caregivers' perspectives and all participants were identified as parents of children with IDD who were transitioning into adulthood. However, to further explore FQOL it would be interesting to interview other family members such as siblings or individuals with IDD to establish their perspectives on their families' FQOL and determine what they value, and what

domains they see as quality or find challenging and compare it to their parents'

views. An individual case study approach where a family is studied, and each family

member is interviewed individually and then together as an entire family unit may

be an interesting research endeavor to examine FQOL in the future.

Participants' in this study highlighted areas in their lives where their needs are

not being met and where they are not satisfied, including support from others and

support from disability related services. Although these findings are based on a

small sample and cannot be readily generalized to the greater population, they do

support results from other recent FQOL studies as indicated in the previous chapter.

As such, the domains support from others and support from disability related

services should be researched further and accessed separately from the other seven

life domains so that we can delve more deeply into how and where these areas are

lacking and how these areas can be addressed to provide families with greater

support.

Concluding Remarks

This study examined how family quality of life is affected when a member with

disabilities transitions into adulthood. This research approached this experience of

transition by studying a small sample of families with members who have IDD and

who are or have transitioned into adulthood, focusing on their perceptions of their

FQOL**.** The parents who identified as the primary caregivers in these families

reflected on challenges associated with their current supports systems, or areas

where such supports were lacking. Additionally, they highlighted family strategies

for success and discussed areas where their FQOL maintained a relatively high level

of satisfaction. Participants reported on the large amount of responsibilities they have and how the majority of their time and effort goes into advocacy and care for their child with IDD as they moved through their period of transition into adulthood. Consequently, many parents hoped for more opportunities and options to enhance their own quality of life and their family's quality of life during this time of transition.

As noted in the existing FQOL literature, families are essential in supporting a positive QOL for individuals with IDD, but in order for families to effectively support their transitioning member, they require opportunities to ensure the needs of other members of their immediate family are fulfilled and their overall QOL is sustained. In this research, participants reported a lack of support from the adult disability service providers. This gap between expectation and experience negatively influences their FQOL in several key areas of life. Of these, the most significant perception was the convoluted and inconsistent disability services, because navigating these services is difficult and time consuming, leading families to exhaust all their personal resources in order to attain the necessary services and supports for their family member with IDD. Consequently, transitioning individuals and their families in the present study often felt isolated and without the necessary funding and support to move forward in the transition process. They reported difficulty in maintaining or improving their FQOL in many of the interconnected domains addressed in this research.

Additionally, participants also reported a lack of support from others, including their extended family members and friends. However, they did recognize

the significant supports they receive from other families within the local disability community. This qualification of 'support' suggests that the FQOL literature could benefit from re-conceptualizing the 'support from others' domain, for this may further the field's understanding of those positive reciprocal relationships that families depend upon within their local disability community. This might enable families and local service providers to foster these relationships and create more opportunities for sharing resources and information. As community ties appear to strengthen families' understanding of the transition process and provide encouragement in times of isolation, it is important that social connections for all family members are sustained.

Participants in this research suggested that prioritizing the family's community connections, leisure and recreational activities and social relationships, as well as providing more accessible and consistent support which, in turn may provide opportunities for all family members to realize their own needs and pursue activities and interests either individually or as a family unit, may positively influence their family's overall FQOL, providing a stronger family foundation and social context for the individual with IDD as they transition into adulthood.

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Appendices

Appendix A: Agency Request Form

University of Victoria

Agency Request Form

Eighteen and up: Researching disability and family quality of life in transition

This letter is a request for _____'s assistance with a research study that I, Kierstyn Butler am conducting as part of my Master's degree in the Department of Child and Youth Care at the University of Victoria. This research study is being conducted under the supervision of Drs. Sibylle Artz and Roy I. Brown. You may contact them by phone or email with any questions or concerns regarding this study.

Sibylle Artz █████████   Email: ██████████
Roy I Brown █████████   Email: ████████████

The purpose of this research study is to explore how families perceive their family quality of life while their family members with intellectual or developmental disabilities transition from adolescence to adulthood. The study aims to explore what families believe are their greatest strengths and supports as well as their greatest needs and challenges to their quality of life as their child or family member transitions from adolescence to adulthood.

It is my hope to connect with families who use your organization's services. My objective is to survey parents or family members who are considered main caregivers to individuals with intellectual or developmental disabilities who are between the ages of 18-26 and are currently or have recently transitioned from adolescence to adulthood.

To protect the privacy of your clients and families, I am asking for your assistance in recruiting participants. If you are willing to participate, I will send you an invitation email to send to families who use your services. My contact information will be included in the invitation if parents or family members are interested in participating and want more information.

The study consists of a survey and subsequent focus group. Once participants have agreed to take part in the study they will be mailed the *Family Quality of Life Survey – Short Version: Main caregivers of individuals with intellectual and developmental disabilities* to complete. It is estimated that survey completion will take 30 minutes.

When completed, participants will be asked to return the survey using the self addressed and stamped envelope they received with the survey package. In addition to the survey, participants will be invited to take part in a focus group discussion about family quality of life that will be conducted at a later date. However, participants may decline participating in this group discussion.

Please be advised that your agency and the identity of parents and family members who agree to participate within the study will remain anonymous and no names will appear in the thesis. Data retrieved from the survey and focus group will be aggregated, so no agency or participant can be identified or connected to any aspect of the data.

There are some potential risks to parents and family members participating in this research. As the topic of this research is of a personal and sensitive matter participants may have an emotional or psychological response while reflecting upon and answering questions about their family quality of life. To mitigate these effects, a clinical counsellor will be available to participants for consultations during the research process.

There are several potential benefits of your assistance in this research for both disability agencies and participants, these include:

1. Parents and families will receive the opportunity to express their ideas and opinions on what is going well and what support is needed when a family member with disabilities transitions into adulthood.

2. If participants are part of the focus group they will have the opportunity to learn about new strategies and community resources, and may gain a sense of comfort or hope by sharing and listening to stories, ideas and opinions of other families with common concerns and experiences.

3. This study may provide agencies and organizations for individuals with disabilities with information regarding what families perceive as their greatest supports, strategies, needs, and challenges when their child/family member with a disability is transitioning into adulthood and moving into adult focused programs. With this information, agencies may be better equipped to assist families and to provide more effective support while their family member is transitioning into adulthood.

Participation is completely voluntary. Parents and family members are invited to make their own independent decision to participate. Throughout the process, participants will be free to withdraw from the study at any time without any consequences and without needing to discuss or explain their withdrawal. If participants do withdraw from the study, their survey answers will only be used if they give permission. Their participation within the focus group will be impossible to remove, however data from the focus group will only be used in a summarized form and their participation will remain anonymous.

Data will be kept in a password-protected computer file and disposed of, once all requirements for the thesis are completed. It is anticipated that results will be shared in the following ways: thesis oral presentation, posted online at *"UVicSpace"*, and potentially within a published article or chapter.

If you have any further questions or would like any additional information that may assist you in making a decision regarding your participation please contact my research supervisors, Sibylle Artz and Roy Brown or myself. I can be contacted by email at Kierstyn@uvic.ca and Sibylle Artz and Roy Brown can be contacted via the information provided above.

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.

If you would like to participate in this research study and assist Kierstyn Butler with participant recruitment, please contact her via email at Kierstyn@uvic.ca. If your agency chooses to participate, Kierstyn will send an approval letter that requires your signature for the purposes of research ethics.

Thank you for your time and consideration, I look forward to hearing from you.

Sincerely,

Kierstyn Butler
Master's Candidate
Department of Child and Youth Care
University of Victoria

Appendix B: Agency Approval Form

University of Victoria

Agency Approval Form

Eighteen and up: Researching disability and family quality of life in transition

Attention: University of Victoria Human Research Ethics Board

I have reviewed the research outline and recruitment request titled "Eighteen and up: Researching disability and family quality of life in transition" being conducted by Kierstyn Butler of the School of Child and Youth Care at the University of Victoria. I have had the opportunity to ask questions and gather any additional details of the study that came to mind for me. I understand what Kierstyn is asking of the participants, and note that the identity of the organization and participants will remain anonymous. I have been informed that this organization and the study participants may withdraw at anytime without any consequence. Therefore, I agree to assist Kierstyn in recruiting parents and family members from for this research study. I have the authority to grant this request. If I have any further questions about this research study, I understand that Kierstyn can be reached via e-mail at Kierstyn@uvic.ca. I also understand that these questions can be directed to Kierstyn's research supervisors Sibylle Artz at ▮▮▮▮▮▮▮▮ or Roy Brown at ▮▮▮▮▮▮▮▮▮▮

_____   _____
Director Name   Organization

_____   _____
Director Signature   Date

_____   _____
Witness Name   Date

_____
Witness Signature

Appendix C: Participant Invitation

University
of Victoria

Participant Invitation

My name is Kierstyn Butler. I am a graduate student in the School of Child and Youth Care at the University of Victoria. I am conducting a research study called *Eighteen and up: Researching disability and family quality of life in transition* to fulfill the requirements of my Master's degree. I would like to extend an invitation to you to participate in this study.

The purpose of this research study is to explore how families perceive their family quality of life while their family members with intellectual and developmental disabilities transition from adolescence to adulthood. This study aims to explore what families believe are their greatest strengths and supports as well as their greatest needs and challenges to their quality of life as their child or family member transitions from adolescence to adulthood.

You are eligible to participate in this study if you are a parent or family member who is considered the main caregiver of an individual with intellectual and developmental disabilities, who is between the ages of 18-26 and is currently or has recently transitioned from adolescence to adulthood.

Participation in this study involves the completion of the *Family Quality of Life Survey – short version: Main caregivers of people with intellectual and developmental disabilities*. The survey will ask questions regarding certain aspects of your family quality of life while a family member is transitioning into adulthood, and how important, accessible and supported these aspects are. The survey will be sent through the mail and will need to be returned to Kierstyn Butler when completed. Survey participation will require approximately 30 minutes of your time.

In addition to the survey, participants are invited to participate in a focus group that will further explore and discuss family quality of life. Discussion will include supports and challenges you have experienced and advice and strategies you have for other families that have family members with disabilities who are transitioning into adulthood. It is anticipated that the focus group will take approximately 1 hour.

Participation in this study is completely voluntary, and participants may withdraw at any time without any consequences. Participants can choose to

complete only the survey and do not have to participate in the focus group if they do not wish to do so.

This study had been reviewed and approved by the University of Victoria Human Ethics Office Board. If you have any questions or concerns you may contact them at 250-472-4545 or ethics@uvic.ca.
If you are interested in participating in this study or have any questions please contact me at Kierstyn@uvic.ca.

Thank you in advance for considering this request.

Kierstyn Butler
MA Candidate
School of Child and Youth Care
University of Victoria
P.O. Box 1700, STN CSC
Victoria, BC V8W 2Y2
Canada

Appendix D: Participant Instruction Sheet

University of Victoria

Participant Survey Instructions

Dear participant,

Thank you for volunteering to participate in the study entitled *Eighteen and up: Researching disability and family quality of life in transition*. Your participation is appreciated and will contribute to furthering knowledge and understanding of family quality of life while a family member with intellectual and developmental disabilities is transitioning from adolescence to adulthood. Additionally, it may assist in providing services providers and agencies with recommendations to help support individuals with intellectual and developmental disabilities and their families during times of transition.

To begin, please read and sign the following consent form. If you have any questions or concerns, please do not hesitate to contact Kierstyn Butler via the contact information provided. At the end of the consent form please take note of the question regarding the focus group discussion. If you are interested in participating in the focus group please check the appropriate box. An additional consent form is provided for you to keep for further reference.

Next, please read through and answer the questions on the survey. Once completed, please place both the signed consent form and survey into the pre addressed and stamped envelope and mail it back to the primary researcher, Kierstyn Butler.

Please note participants can contact the primary researcher at any time with questions or concerns during the research process.

Thank you for you time and engagement in this research study.

Sincerely,

Kierstyn Butler
Master's Candidate
Department of Child and Youth Care
University of Victoria

Appendix E: Participant Consent Form

Participant Consent Form

Eighteen and up: Researching disability and family quality of life in transition

You are invited to participate in a study entitled *Eighteen and up: Researching disability and family quality of life in transition* that is being conducted by Kierstyn Butler.

Kierstyn Butler is a graduate student in the department of Child and Youth Care at the University of Victoria. You may contact her if you have further questions by phone ███████████ or via email at Kierstyn@uvic.ca

As a graduate student, I am required to conduct research as part of the requirements for a Masters degree in Child and Youth Care. It is being conducted under the supervision of Sibylle Talmon-Gros Artz and Roy I Brown. You may contact them by phone or email with any questions or concerns regarding this study.

Sibylle Talmon-Gros Arts ███████████ Email: ███████████
Roy I Brown ███████████ Email: ███████████

Purpose and Objectives
The purpose of this research study is to explore how families perceive their family quality of life while their family members with intellectual or developmental disabilities transition from adolescence to adulthood. The study aims to explore what families believe are their greatest strengths and supports as well as their greatest needs and challenges to their quality of life as they move through the transition of their child or family member from adolescence to adulthood.

Importance of this Research
Research of this type is important as exploring families' perspectives on what contributes to their quality of life may provide them and other families with strategies and supports that can assist in the development of a meaningful quality of life while their children/family members with disabilities transition into adulthood. Additionally, this study may provide service providers and disability agencies with recommendations on how they can address families' greatest needs and practice more effective ways of supporting families and their family quality of life as their children/family members transition into adulthood.

Participants Selection

You are being asked to participate in this study because you are a parent or family member who is considered to be the main caregiver of an individual with intellectual or developmental disabilities who is between the ages 18-26 and is currently transitioning or has recently transitioned from adolescence to adulthood.

What is Involved

If you consent to voluntarily participate in this research, your participation will include completing the *Family Quality of Life Survey-Short Version: Main caregivers of people with intellectual and developmental disabilities.* Once you have completed the survey please send it and the consent form back via mail using the included pre-addressed and stamped envelope.

In addition to the survey you are invited to participate in a focus group discussion following the analysis of completed surveys. The focus group discussion will include supports and challenges you have experienced, and advice and strategies you have for other families that have family members with disabilities who are transitioning into adulthood. Participants may decline in participating in the focus group discussion. The focus group will be audio recorded and a transcription of the discussion will be made.

Inconvenience

Participation in this study may cause some inconvenience to you, including time needed to complete the survey and time and travel needed for participating in the focus group discussion.

Risks

There are potential risks associated with this research as it focuses on personal and family matters. As such, participants may experience an emotional or psychological response when reflecting upon and answering questions about their family's quality of life. To mitigate these effects, a clinical counsellor will be available to participants for consultations during the research process. Rob Baker is a registered clinical counsellor with experience working with individuals with disabilities and their families. Rob can be reached by phone ████████████ or via email at ████████████████████████████ to schedule a consultation.

Benefits

The potential benefits of your participation in this research include, having the opportunity to express ideas and opinions and provide agencies with information regarding what families perceive as their greatest strategies, supports, needs and challenges for their quality of life when their child or family member with disabilities is transitioning into adulthood. Additionally, families shared perceptions may initiate change in service programs and assists agencies in providing more effective support for families while their child or family member is transitioning into adulthood.

Voluntary Participation
Your participation in this research must be completely voluntary. Your decision to participate or not participate will not affect you or your family members position/participation within the agencies your family members currently attend. If you do decide to participate, you may withdraw from the study at any time without any consequences or any explanation. If you do withdraw from the study your survey data will be used only if you give permission. Data from the focus group will be impossible to remove, however as data will be only used in summarized form your contribution to the discussion will remain anonymous.

On-going Consent
If you decide to participate in the focus group, I will supply a second consent form at the time of the focus group discussion. This second consent form will ensure that you continue to give your consent to participate in this research.

Anonymity
In terms of protecting your anonymity, no names or identifying information will be used in the thesis. Each participant and service agency will be given a pseudonym such as AP1, or BP2 so they will remain anonymous.

Confidentiality
Your confidentiality and the confidentiality of the data will be protected by a password protected computer and file.

Dissemination of Results
It is anticipated that the results of this study will be shared with others in the following ways: thesis, oral presentation, posted online at *"UVicSpace"*, and potentially within a published article or chapter. Additionally, participating agencies and participants will be provided with access to the results of this study.

Disposal of Data
Data from this study including survey paper copies and audio recording and transcriptions from the focus group will be disposed of and deleted when all requirements for the thesis are completed.

Contacts
Individuals that may be contacted regarding this study include Kierstyn Butler, Sibylle Artz and Roy Brown. Contact information is included at the beginning of the consent form.

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).

Your signature below indicates that you understand the above conditions of participation in this study, that you have had the opportunity to have your questions

answered by the researchers, and that you consent to participate in this research project.

Name of Participant	*Signature*	*Date*

As noted above we will be holding a focus group with parents and family members to further explore and discuss family quality of life when a family member with disabilities is transitioning from adolescence to adulthood. If you are interested in participating and would like to be contacted please check the appropriate box.

☐ **Yes, I am interested in participating in the focus group. Please contact me with further information.**

☐ **No thank you, I am not interested in participating in the focus group.**

A signed copy of this consent for must be sent to the researcher. A second copy of this consent form is provided for your reference.

Appendix F: Interview Guide Questions

1) How would describe your perception of family quality of life?

2) What are some major factors that contribute positively to your families' quality of life?

3) What are some major factors that contribute negatively to your family quality of life?

4) How has your family quality of life been affected by your family members transition from adolescence to adulthood?

5) What are some goals that you have for your family?

6) What are some ideas or strategies that you believe would be important to tell other families entering this transition period with their family members with intellectual or developmental disabilities?

7) How do service providers promote a positive contribution to your family's quality of life?

8) What other services do you believe would be beneficial for your family quality of life that disability organizations/agencies and government could provide?

9) What supports have your found most beneficial during you family members transition from adolescence to adulthood.

10) Could you comment on how community interaction or leisure and recreation have affected your family during your child's transition into adulthood?

11) Is there anything else you would like to add with regard to you family quality of life that we have not touched upon yet?

Appendix G: Continuing Participant Consent Form

Participant Consent Form

Eighteen and up: Researching disability and family quality of life in transition

You are invited to continue participating in a study entitled *Eighteen and up: Researching Disability and Family Quality of Life in Transition* that is being conducted by Kierstyn Butler.

Kierstyn Butler is a graduate student in the department of Child and Youth Care at the University of Victoria. You may contact her if you have further questions by phone ▮▮▮▮▮▮▮▮▮ or via email at Kierstyn@uvic.ca

As a graduate student, I am required to conduct research as part of the requirements for a Master's degree in Child and Youth Care. It is being conducted under the supervision of Sibylle Talmon-Gros Artz and Roy I Brown. You may contact them by phone or email with any questions or concerns regarding this study.

Sibylle Talmon-Gros Arts ▮▮▮▮▮▮▮ Email: ▮▮▮▮▮▮▮
Roy I Brown ▮▮▮▮▮▮ Email: ▮▮▮▮▮▮▮

Purpose and Objectives
The purpose of this research project is to examine the perspectives of parents or family members who are considered main caregivers, on their family quality of life, as their children or family members with intellectual and developmental disabilities transition from adolescence to adulthood. The study aims to explore what families believe are their greatest strengths and supports as well as their greatest needs and challenges to their quality of life as they move through the transition of their child or family member from adolescence to adulthood.

Importance of this Research
Research of this type is important as exploring families' perspectives on what contributes to their quality of life may provide them and other families with strategies and supports that can assist in the development of a meaningful quality of life while their children/family members with disabilities transition into adulthood. Additionally, this study may provide service providers and disability agencies with recommendations on how they can address families' greatest needs and practice

more effective ways of supporting families and their family quality of life as their children/family members transition into adulthood.

Participants Selection
You are being asked to participate in this study because you are a parent or family member who is considered to be the main caregiver of an individual with intellectual or developmental disabilities who is between the ages 18-26 and is currently transitioning or has recently transitioned from adolescence to adulthood.

What is Involved
If you consent to continue participating in this research, your participation will include meeting with a small group of other parents and families who are main caregivers of individuals with intellectual or developmental disabilities to discuss family quality of life and their family members transition from adolescence to adulthood.

Inconvenience
Participation in this study may cause some inconvenience to you, including time and travel needed to attend focus group discussion.

Risks
There are potential risks associated with this research as it focuses on personal and family matters. As such, participants may experience an emotional or psychological response when reflecting upon and answering questions about their family's quality of life. To mitigate these effects, a clinical counsellor will be available to participants for consultations during the research process. Rob Baker is a registered clinical counsellor with experience working with individuals with disabilities and their families. Rob can be reached by phone ███████████ or via email at ████████████████████████ to schedule a consultation.

Benefits
The potential benefits of your participation in this research include, having the opportunity to express ideas and opinions and provide agencies with information regarding what families perceive as their greatest strategies, supports, needs and challenges for their quality of life when their child or family member with disabilities is transitioning into adulthood. Additionally, families shared perceptions may initiate change in service programs and assists agencies in providing more effective support for families while their child or family member is transitioning into adulthood.

Voluntary Participation
Your continued participation in this research must be completely voluntary. Your decision to participate or not will not affect your or your family members position/participation within the agencies your family members currently attend. If you do decide to participate, you may withdraw at any time without any consequences or any explanation. If you do withdraw from the study, data from the

focus group will be impossible to remove, however as the data will be in a summarized form participants identity will be anonymous.

Anonymity

In terms of protecting your anonymity, no names or identifying information will be used in the thesis. Each participant and service agency will be given a pseudonym such as AP1, or BP2 so they will remain anonymous.

Confidentiality

Due to the nature of the focus group, the confidentiality of participants cannot be guaranteed. However, before the group discussion occurs participants will be encouraged to keep what they hear and see confidential. Participants confidentiality and the confidentiality of the data will be protected by a password protected computer and file.

Dissemination of Results

It is anticipated that the results of this study will be shared with others in the following ways: thesis oral presentation, posted online at *"UVicSpace"*, and potentially within a published article. Additionally, participating agencies and participants will be provided with access to the results of this study.

Disposal of Data

Data from this study including survey paper copies and audio recording and transcriptions from the focus group will be disposed of and deleted when all requirements for the thesis are completed.

Contacts

Individuals that may be contacted regarding this study include Kierstyn Butler, Sibylle Artz and Roy Brown. Contact information is included at the beginning of the consent form.

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).

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

Name of Participant	*Signature*	*Date*

The researcher will take a signed copy of this consent form and a copy will be left with you.