Parent-to-Parent Peer Support and Family Quality of Life

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A dissertation

submitted in partial fulfillment of the

requirements for the degree of


Doctor of Education


University of Washington

2016

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Program Authorized to Offer Degree:

College of Education

University of Washington

**Abstract**

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This study utilized the *Beach Center Family Quality of Life Scale (FQOLS)* to explore the impact of parent-to-parent peer support and demographic characteristics on family quality of life (FQOL) ratings, and expanded the scope of the instrument to include adults. Data analysis provided descriptive statistics for respondent demographics as well as each *FQOLS* item and domain. Independent-sample t-tests were used to determine whether a difference existed between sample means of respondents who participated in parent-peer mentoring programs and those who did not. The majority of participants indicated feeling neutral to satisfied with their overall FQOL. Families who participated in parent-to-parent peer mentoring programs indicated increased FQOL ratings, but none reached significance. Future implications for development of support models supporting FQOL is discussed.

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# Acknowledgements

First, I would like to thank Dr. Clayton Mork, for seeing something in me that I did not see in myself, and for encouraging me to pursue opportunities for leadership in my field. This is one of those turning points in my life, when I look back and realize how your early support in my career had a tremendous influence on the journey which led me to this point.

I am also extremely grateful to my friends and family through this process. It has been a long time coming, and I appreciate the sacrifices made on my behalf so that I could complete this work. So many have picked up the slack in other parts of my life, cheered me on, and even rolled up their sleeves to dive into this world with me. Jay, Michelle, Dorie, Mahala, Jessie, Kristina, Colby – your support really helped carry me through some challenging times. My deepest gratitude though, goes to my good friend Ceinan, for innumerable hours taken out of her own life, to be there for me in whatever way I needed: administrative assistant, editor in chief, technological advisor, chief cook and dishwasher, mental and physical health consultant, personal statistician, taxi driver, whip cracker, cheerleader, and probably more. I don't think I could have done this without you.

Of course, many thanks go to my committee for their patience and flexibility, especially as we came to the end of our time together. To Dr. Ilene Schwartz for your thoughtful analysis and insight. To Dr. Elizabeth West for your willingness to answer any question, and ability to talk me off the ledge when need be. And to my advisor, Dr. Carol Davis, for her commitment to helping me finish this work and really pushing me when the time came.

Most importantly, I would like to acknowledge my students and their families for all they have taught me and for the inspiration to continue seeking a deeper understanding of their lives, both in school and out. Cassie, Heidi, and Deb – I certainly grew professionally as a result of our time together; but more importantly, I grew as a person because of you. I will be eternally grateful for the time we spent together and the life-changing insights that came my way by means of you and your children. I hope to continue in work that will lead to meaningful change and improvement in quality of life and well-being for you and your families.

**CHAPTER ONE**

**Introduction**

The study of Family Quality of Life (FQOL) is a relative newcomer to the world of

research, appearing in the late 1990s as an offshoot from the study of Quality of Life (QOL) for

individuals with intellectual and developmental disabilities (IDD) (Brown, Anand, Fung, Isaacs,

& Baum, 2003; Brown, MacAdam-Crisp, Wang, & Iarocci, 2006).  In an effort to define the term

*quality of life*, Schalock et al. (2002) stated that "'quality' makes us think about the excellence

associated with human values, such as happiness, success, wealth, health, and satisfaction,

whereas, 'of life' indicates that the concept concerns the very essence or essential aspects of

human existence."  Early conceptualizations of IDD emphasized personal deficits in comparison

to typically developing peers, and focused on treatment through medical and technological

interventions.  The QOL construct came about in response to a growing awareness of contextual

influences on outcomes for individuals with IDD, an increased focus on community-based

services and assessment, and new social priorities on person-centered planning, self-

determination, and individual well-being (Schalock et al., 2002).  Domains representative of this

paradigm shift were identified to describe and measure QOL, and in addition to self-

determination and well-being, included interpersonal relationships, personal development, social

inclusion, and disability-related rights (Cummins, 1996; Felce, 1997; Goode, 1997; Schalock et

al., 2002).  This new framework provided a means to understand and address the needs of

individuals with IDD through a new lens, exploring the influence of environmental factors on

personal well-being across these aspects of life (Brown & Brown, 2003; Brown, Schalock, &

Brown, 2009; Schalock, Gardner, & Bradley, 2007).  As QOL study progressed, family well-

being emerged as a fundamental component in positive outcomes for individuals with IDD

(Brown & Brown, 2003; Brown et al., 2009; McIntyre, Kraemer, Blacher, & Simmerman, 2004; Park et al., 2003; Poston et al., 2003; Schalock & Luckasson, 2004; Turnbull & Stowe, 2001), launching FQOL as its own field of study.

The theoretical shift in disability studies from a deficit model to a more holistic approach, coincided with logistical changes in the disabilities population, emphasizing the need for research on the family context in relationship to outcomes for individuals with IDD.  For example, deinstitutionalization and medical advances increased the number of individuals with intellectual disabilities living in local communities, impacting familial care-giving roles and the types of services needed for support (Brown et al., 2006).  Increasing expectations were placed on the family unit to accept and maintain primary responsibility in the care of their loved ones with IDD, in service provision, support coordination, and advocacy.  These new obligations created a dramatic impact on family behavior and lifestyle with increasing demands on emotions, time, and finances, along with new limitations in access to employment and leisure activities (Brown et al., 2006; Brown, et al., 2009; Gardiner & Iarocci, 2012).  Furthermore, because children with IDD became more likely to continue living at home through adulthood, more parents found themselves in the role of life-long caregivers (McConkey, 2005), needing to contend eventually with their own age-related challenges as well as the concerns of their adult children (Minnes, Woodford, & Passey, 2007).

This social evolution, along with the advancement of QOL research as a mechanism to frame our understanding of disability, highlighted family functioning as a primary factor in determining outcomes for individuals with IDD (Brown & Brown, 2003; Brown et al., 2009; Schalock & Luckasson, 2004; Turnbull & Stowe, 2001).  Concepts regarding family functioning derived from family systems theory and focused on interaction between members, relative to

dimensions of communication, cohesion, flexibility, role performance, and coping processes (Olson & Gorall, 2003).  Enhanced family functioning became associated with a number of benefits to individual QOL.  For example, increased parental well-being has influenced positive outcomes in family relationships (Hammarberg, Sartore, Cann, & Fisher, 2014), and provision of supports and resources for young adult members with disabilities.  Positive family relationships, along with adequate supports and services, established a strong correlation with improved QOL (McIntyre et al., 2004), demonstrating the value of family well-being to individual quality of life outcomes.  Evidence further suggested that efforts towards improving both individual and family QOL were closely linked to positive results for individuals with IDD (Brown et al., 2009; Chou & Schalock, 2009; Hu, Wang, & Fei, 2012).  From a professional standpoint, the importance of family functioning to child outcomes became so clear that family-centered service models emerged as best practice in disability policy and service provision (Bailey et al., 1998; Davis & Gavidia-Payne, 2009; Poston et al., 2003; Turnbull, Beegle, & Stowe, 2001), and so that the field could no longer attribute the outcomes for individuals with IDD solely to personal characteristics or program features, but also to the well-being of the family.

The relevance of family functioning to individual QOL prompted further study of factors related specifically to family well-being.  Much of this research focused on the challenges associated with parenting a child with disabilities, exploring issues such as caregiver burden, stress, depression, coping, and adjustment (Al-Krenawi, Graham, & Al Gharaibeh, 2011; Helff & Glidden, 1998; McConkey, 2005; Minnes, Woodford, & Passey, 2007; Summers et al., 2005; Woodman & Hauser-Cram, 2013).  Subsequent studies also emerged, drawing attention to positive and rewarding experiences related by families, such as resilience, connection, personal growth, and enrichment (Bayat, 2007; Dykens, 2005; Hastings & Taunt, 2002; King et al., 2005;

Rapanaro, Bartu, & Lee, 2007).  This literature brought about an increased awareness of the complexities of family dynamics related to disabilities.  With this new understanding, combined with known parallels between individual and family well-being, researchers sought a means to adequately define and measure family quality of life.  It was determined that using a framework similar to that from individual QOL studies could provide for the exploration of disability in terms of family behavior, needs, and priorities, while avoiding use of a deficit-based model (Bailey et al., 1998; Brown & Brown, 2003; Turnbull et al., 2001).

While others have contributed to this literature through exploration of family roles and experiences, two groups have been primarily responsible for initiating the systematic conceptualization and measurement of FQOL. The Beach Center on Disability at University of Kansas (Beach Center on Disability, 2003; Hoffman, Marquis, Poston, Summers, & Turnbull, 2006; Park et al., 2003) and the International Family Quality of Life Project, initiated by a separate team of international researchers (Brown et al., 2006; Isaacs et al., 2007), concurrently developed two unique measures for FQOL based on the individual QOL model.  While there were some differences between the two, they were based on similar theoretical foundations, utilizing domains having to do with topics such as physical, emotional, and financial well-being, family relationships, support from others, and disability-related support (Brown et al. 2003; Park et al., 2003; Turnbull, Poston, Minnes, & Summers, 2007).  Despite some variation in organization and methodology, there was substantial overlap in domain content, suggesting these instruments would likely provide comparable data on FQOL (Rillotta, Kirby, & Shearer, 2010; Samuel, Rillotta, & Brown, 2012).

Findings from these studies have revealed information which helps us better understand the experiences of families including a member with a disability.  In general, families who have

children with IDD tend to report lower satisfaction in FQOL than families with typically developing children, with considerable dissatisfaction expressed across many domains (Brown et al., 2006; Poston et al., 2003).  Additionally, families of children with autism tend to rate their FQOL lower than other families, with or without disabilities, over all domains (Brown et al., 2006; Gardiner & Iarocci, 2012).  Family finances have been found to predict FQOL in some studies (Brown et al., 2006; Cagran, Schmidt, & Brown, 2011; Davis & Gavidia-Payne, 2009; Hu et al., 2012; Wang, Turnbull, et al., 2004), but results have been inconsistent, with satisfaction reported across lower income levels as well (Brown et al., 2003; Neikrug, Roth, & Judes, 2011; Petrowski, Edwards, Isaacs, Baum, & Brown, 2008).  While the literature continues to identify and clarify patterns associated with FQOL, the most predominant trend has been low ratings in domains having to do with receiving support.

Support from others and disability-related support consistently yield the lowest satisfaction ratings of all domains by families of minor and adult children with disabilities (Bertelli, Bianco, Rossi, Scuticchio, & Brown, 2011; Brown et al., 2003; Brown et al., 2006; Cagran et al., 2011; Jokinen & Brown, 2005; Neikrug et al., 2011; Petrowski et al., 2009; Werner, Edwards, & Baum, 2009).  This is cause for concern, as these domains are critical to FQOL.  For example, formal professional support (i.e. that provided by agencies and organizations) has been identified as one of the greatest overall predictors of positive family outcomes and well-being (Davis & Gavidia-Payne, 2009; Dunst, Trivette, & Hamby, 2007; Eskow, Pineles, & Summers, 2011; Summers et al., 2007).  However, many families find challenges in accessing this type of support, encountering long waiting lists with a shortage of information and adequate services (Brown et al., 2003; Gill & Renwick, 2007). Informal social support is also essential as a significant predictor of parental well-being, associated with reduced

depression and stress in families of children with disabilities, and considered by some as an integral component of effective intervention (Davis and Gavidia-Payne, 2009).  Unfortunately, while friends and family may be willing to offer emotional support, they often provide little to no practical assistance in daily life (Brown et al., 2003; Kerr & McIntosh, 2000).  Furthermore, many parents have reported taking little initiative in obtaining needed support, perhaps not wanting to ask for help, or believing it is unavailable (Brown et al., 2003).  The importance of support to positive FQOL outcomes, combined with consistently poor ratings in this domain across studies, underscores the necessity of addressing family needs in this area.

By understanding the factors that influence FQOL, we may better identify services to best address the needs of families and individuals with disabilities.  In addition to improved resiliency (Cox, Mills-Koonce, Propper, & Gariepy, 2010) and overall positive outcomes for families accessing community resources and support systems (Davis & Gavidia-Payne, 2009; Eskow et al., 2011; Gill & Renwick, 2007), there are further considerations to enhance service provision. Parallels have been identified between established individual QOL domains and the goals of IDEA (Individuals with Disabilities in Education Act), which suggest educational implications for this framework (Turnbull, Turnbull, Wehmeyer, & Park, 2002).  Providing support specific to individual family needs, targeted directly to FQOL domains, has been argued as a critical element to improving outcomes for these families (Schippers & von Boheemen, 2009; Summers et al., 2007).  Examples suggested for such services have included parent training and education programs, provision of respite care, day programs for members with disabilities, family counseling, and peer support (Brown et al., 2003; Dunlap & Fox, 2007; Friend, Summers, & Turnbull, 2009; Gill & Renwick, 2007).

Parent-to-parent support programs are an established option for mothers and fathers,

well-suited to address peer support needs and provide an avenue to obtain relevant information

about disabilities, services, and strategies for managing day-to-day life.  These programs

typically match trained mentoring parents with other parents seeking assistance in particular

areas.  Parent-to-parent support groups were founded on the premise that parents of children with

special needs are uniquely qualified to help each other (Singer et al., 1999).  An early study

found these programs to provide a cost-effective model that provided parents with the

opportunity to share feelings, experiences, and information.  Parent peer support groups also

contributed to reduced feelings of isolation, and allowed exploration of parental needs separate

from those of their children (Winch & Christoph, 1988).  Further study upheld these findings,

detailing additional social, emotional, and practical benefits described by families across a wide

range of demographics (Ainbinder et al., 1998; Hammarberg et al., 2014; Ireys Chernoff, DeVet,

& Kim, 2001; Kerr & McIntosh, 2000; McCabe, 2008; Silver**,** Ireys, Bauman, & Stein, 1997;

Singer et al., 1999; Tadema & Vlaskamp, 2010; Turnbull, Blue-Banning, Turbiville, & Park,

1999).

    While the parent-to-parent support model may not appeal to all families, there is reason

to believe that organized parent peer support may be of interest to many.  When given the

opportunity, the majority of parents have expressed a desire to connect with others in similar

circumstances (Kerr & McIntosh, 2000; McConnell, Breitkreuz, & Savage, 2012), showing

enthusiasm and an eagerness to help each other (McCabe, 2008).  Parents participating in such

programs have reported that peer support offered opportunities to learn from the experiences of

other parents in similar circumstances, with no comparable alternative from other sources (Kerr

& McIntosh, 2000).  Additionally, when parent-to-parent support programs were offered in

conjunction with services for their children, some parents reported finding greater value in their

adult peer connections than in the coinciding child services (McCabe, 2008).  Further, parents also reported appreciation for the reciprocal nature of this approach, with benefit perceived from both the giving and receiving of assistance (Ainbinder et al., 1998).

## Statement of Problem

Parent-to-parent peer support has been identified as a successful support model for families of individuals with disabilities.  Satisfaction with emotional well-being and disability-related services persists as the lowest rated of all FQOL domains consistently across multiple studies.  Parent-to-parent support may be a means to improve FQOL for families of minor and adult children with disabilities.  With formal and informal support identified among the greatest predictors of positive outcomes for families, and the interconnection established between family and individual quality of life, a considerable risk may exist to quality of life for individuals with disabilities and their families.  Application of FQOL measures to assess service models such as parent-to-parent support is a means to inform practice and guide services to increase positive outcomes for individuals with disabilities and their families.

## Significance of Study

The literature on FQOL and its application is still somewhat limited due to its recent emergence as a specific field of research.  This descriptive study expands the literature, by extending use of the *FQOLS* to include families of adults with disabilities, and by exploring the impact of parent-to-parent peer support and demographic factors on FQOL across the United States.  In addition, this study accounts for circumstances such as family trauma and time since diagnosis, which have been suggested to impact FQOL (Gardiner & Iarocci, 2012; Levison, 2014).  It offers a comparison of FQOL ratings across age groups and disability types, while much of the literature focuses on specific categories such as early childhood or autism.  Use of

the family as a unit of measurement supports its contextual relevance to outcomes for individuals with disabilities as presented in the literature, and provides an increased understanding of FQOL in general.  In the field of disability support, data collected from this study will provide useful information to inform funding opportunities, more insightful policy development, and the enhancement of services, by directly addressing parent-referenced FQOL domains.

**Purpose**

The purpose of this study is to survey parents and caregivers of individuals with disabilities to describe their Family Quality of Life (FQOL) and examine the potential influence of participation in parent-to-parent peer mentoring programs and other helpful supports on FQOL.  The resulting data is intended to inform our practices and development of services for families of individuals with disabilities.

The following research questions were examined:

1. What is the FQOL of families, identified by parents/guardians of minor and adult children with disabilities living at home in the United States?

2. Are there differences in FQOL of families who participate in parent-to-parent peer mentoring programs and those who do not.

3. Do other relationships exist between family and individual demographics (e.g., disability, age of child, time since diagnosis, size of community, and ethnic identity and FQOL)?

## CHAPTER TWO

## Literature Review

**Individual Quality of Life**

In order to best understand FQOL, it may be helpful to consider the context of individual QOL from which it arose.  According to Brown et al., (2009), there were a number of factors which contributed to the concept of quality of life as a point of focus in disabilities support, leading to the development of the QOL construct.  The normalization movement of the 1960s paved the way, demanding community-based services along with outcome measures for community life.  At that time, awareness was building around the impact of social values, perceptions, and environmental conditions on individuals with disabilities.  Emphasis in the field of IDD moved from medical and technology-based remedies to individual human rights, consumer empowerment, person-centered planning, self-determination, and overall well-being. The QOL model provided a holistic approach which addressed the complexities of daily life, and produced a new framework to examine and resolve challenges faced by individuals with IDD.

Great progress has been made in the conceptualization and measurement of QOL in the field of IDD, though initially difficult to quantify empirically (Cummins, 1996; Felce, 1997; Goode, 1997; Schalock, 1996, 1997, 2000).  A number of QOL measures have been developed and validated since 1990 in this area (Cummins, 1991; Summers et al., 2005; Isaacs et al., 2007; Lin et al. 2009).  Much of this work has been credited to a group of international researchers through the International Association for the Scientific Study of Intellectual Disabilities' (IASSID) Quality of Life Special Interest Research Group (QoL-SIRG).  This group developed a consensus document focusing on conceptualization, measurement, and application of the QOL construct (Schalock et al., 2002).  A key feature of this framework was the incorporation of

domains measuring the areas of emotional well-being, interpersonal relationships, material well-being, personal development, physical well-being, self-determination, social inclusion, and disability-related rights (Cummins, 1996; Felce, 1997; Goode, 1997; Schalock et al., 2002). Other studies have shown these general aspects of life appear to be valued across cultures, despite variation in belief, practice, and availability of resources (James, 1997; Keith & Schalock, 2000; Renwick, Brown, & Raphael, 2000). The QOL literature explores how individual well-being is influenced by environmental factors across these domains (Brown & Brown, 2003; Brown et al., 2009; Schalock et al., 2007).

Quality of Life study has lead us to re-examine both how we support individuals with disabilities and how we define the concept of disability overall. Historically, this population has been viewed as inherently limited, with services primarily focused on basic care needs. In contrast, disability is now increasingly considered to be imposed by mainstream culture through environmental social norms and construction (Brown et al., 2009). QOL is considered to be enhanced within typical cultural environments, especially those that take advantage of naturally occurring resources available from family, friends, neighbors, and other people (Keith, 2001). This necessitates accommodation as a goal in our local communities, in order to support a relatively new assumption that all people deserve lives of quality (Brown et al., 2009). These new appraisals of disability continue to move us away from previous deficit-based paradigms and to encourage innovation supporting emotional well-being, self-determination, and improved life conditions for individuals with IDD (Samuel, Hobden, LeRoy, & Lacey, 2012).

Growing awareness of environmental influences (e.g., services, resources, inter-personal relationships, etc.) on QOL has led to more application-based research, exploring avenues towards observable improvement in the lives of individuals with IDD (Schalock 2004; Brown &

Brown 2005; Brown et al. 2009; Verdugo & Schalock, 2009; Zuna, Turnbull, & Summers, 2009).

This research has examined the impact of economic and resource allocation, disability reform

and self-advocacy, outcomes demonstrating enhanced well-being as a result of intervention, and

the extent to which society can provide appropriate support at the personal and community level

(Brown et al., 2009).  The literature describes a systematic approach to application of the QOL

framework, which typically involves a collaboration between the individuals with IDD, their

family members, and service providers (Brown, Bayer, & Brown, 1992; Brown & Brown, 2003;

2005; Brown et al., 2009).  The focus is placed on the priorities of persons with IDD,

encouraging self-determination to the greatest extent possible.  Systematic interventions to

address priorities are then implemented, evaluated, and modified based on data analysis.

Professionals are expected to work within the QOL framework and respect ethical boundaries,

acknowledging the potential for wide variability between and within groups, and the possibility

that individuals may change performance, needs, or choices over short periods of time (Brown et

al., 2003).  This process reflects core values of personal choice and empowerment for individuals

with IDD, which have been a foundation in the conceptualization of the QOL framework

(Turnbull, Turnbull, & Blue-Banning, 1994; Brown et al., 2003; Isaacs et al. 2007).

The development of the QOL construct has allowed for a new approach in understanding

and addressing the needs of individuals with disabilities.  This model has been useful in

assessment, intervention, professional practice, policy, and research (Brown & Brown, 2003),

and has enabled the examination of a broader range of contextual factors than in the past (Brown

et al., 2006).  With the evolution of study in this area, the importance of family functioning in

relationship to QOL has emerged as a priority (Brown & Brown, 2003; Brown et al., 2009;

Schalock & Luckasson, 2004; Turnbull & Stowe, 2001), and it has been argued that a framework

similar to that used in QOL may provide valuable information when applied to the family

(Bailey, et al., 1998; Brown & Brown, 2003; Turnbull et al., 2001).  This model allows

exploration of disability in terms of family behavior, needs, and priorities, in order to foster a

high level of well-being despite limitations (Brown & Brown, 2003).  Evidence suggests that

efforts in individual and family QOL are closely connected in the advancement of practice and

policy supporting positive outcomes for individuals with disabilities (Brown et al., 2009; Chou &

Schalock, 2009; Hu, Wang, & Fei, 2012).

**Family Quality of Life**

The emergence of concepts such as those expressed in attachment, ecological, and family

systems theory has influenced a shift in perspective, providing a new understanding of

individuals as interconnected parts of a dynamic whole, who may not be fully understood in

isolation as previously studied (Davis & Gavidia-Payne, 2009; Gardiner & Iarocci, 2012).   For

example, it is now understood that increased well-being for parents improves parent-child

interactions, leading to a positive influence on the child (Hammarberg et al., 2012).  Additionally,

families with higher levels of well-being have demonstrated an enhanced ability to provide

supports and resources to their members with a disability, which have been identified as critical

to individual QOL (McIntyre et al., 2004).

Theoretical progression in the study of IDD contributed to increasing awareness of the

importance of family functioning relative to child outcomes, establishing family centered service

models as a core concept in disability policy and practice (Bailey et al., 1998; Davis & Gavidia-

Payne, 2009; Poston et al., 2003; Turnbull, et al., 2001).  Improved FQOL became identified as a

responsibility (Bailey et al., 1998) and valued outcome from disability-related services by both

providers and parents (Dunst & Bruder, 2002), demonstrating the necessity of FQOL measures to

examine the effectiveness of policies, programs, and treatments.  In addition to changes in how we perceive individuals with disabilities, logistical shifts in demographics support the case to prioritize a better understanding of FQOL as well.  Socio-cultural advancements such as deinstitutionalization and improved medical technology have increased the numbers of individuals with IDD in our communities, subsequently impacting familial care-giving roles and the types of support services needed (Brown et al., 2006).  Family members, particularly mothers, have gained increased responsibilities as the primary providers of intensive and essential support to individuals with IDD, creating a dramatic impact on family behavior and lifestyle (Brown et al., 2006; Brown et al., 2009).  Furthermore, children with IDD are more likely to continue living at home through adulthood, with mothers and fathers as life-long caregivers (McConkey, 2005).  Aging parents are then faced with continuing care for their adult children with disabilities, while contending with limited resources (Jokinen & Brown, 2005) and the eventuality of their own age-related challenges (Minnes et al., 2007).  These changes, and the knowledge of the inter-relatedness of well-being between family and individuals with IDD, lead the field to continue to not only prioritize interventions for individuals with IDD, but also for their families.

The family unit provides the primary developmental context for all children, with or without disabilities, with each member contributing to the foundation of the child's developmental trajectory.  If supports to fulfill this role are not in place, especially for families of children with disabilities, the entire family system is placed at unnecessary risk (Gardiner & Iarocci, 2012).  The additional focus and care necessary for children with disabilities may cause an imbalance in family life (Brown et al., 2006; Brown et al., 2009).  For example, when a family has the increased responsibility of frequent medical appointments, the ability of the

parents to meet the needs of the other family members (e.g., providing meals) becomes reduced.

Families who have children and adult members with IDD have demonstrated more problems

with family functioning, less marital satisfaction, increased caregiver burden, and a lower sense

of family coherence than families with typically developing children (Gardiner & Iarocci, 2012).

The cumulative daily strain of these issues also has a negative impact, increasing parental

feelings of guilt, emotional difficulties, and increased sense of burden and worry (Al-Krenawi,

Graham, & Al Gharaibeh, 2011).  Family outcomes are further impacted by higher rates of

sibling adjustment problems (Fisman, Wolf, Ellison, & Freeman, 2000).  As time goes on, aging

parents who are the primary caregivers for adult children with IDD also experience higher levels

of stress, with poorer physical and mental health than average (Caldwell, 2008; McConkey,

2005; Minnes et al., 2007).  Families caring for a minor or adult child with disabilities are

considered developmentally at risk because they are functioning outside of typical conditions and

have considerable pressures beyond the norm.  They face greater care-giving demands, often

finding themselves overwhelmed and in need of specialized support services which are in limited

supply (Brown et al., 2006; Brown et al., 2009).

     Despite these challenges, it is also important to acknowledge family perceptions of

satisfaction and enrichment related to disability in their lives.  While there are well-documented

challenges in care-giving for a family member with disabilities, research has also identified

aspects of these experiences relating to adaptation, resiliency, hope, and personal growth, with

benefits to the family, such as increased feelings of patience, compassion, and tolerance.

Families often see their loved one with a disability in a positive light, making a meaningful

contribution, and drawing the family closer (Bayat, 2007; Dykens, 2005; Gardiner & Iarocci,

2012; Hastings & Taunt, 2002; King et al., 2006; Lloyd & Hastings, 2009; Woodman & Hauser-

Cram, 2013).

Family experiences and perspectives are quite diverse. In order to best address the needs of families living with disability, their personal values and preferences should be considered (Bailey et al., 1998; Breitenbach, 2004; Brown et al., 2003; Brown et al., 2006). Identifying and prioritizing family preferences and values when designing interventions or identifying supports is referred to as a family-centered approach. The development of the FQOL construct and measurement allows families to have a voice in identifying needed supports, validating strengths, and enhancing various aspects of their lives based on individual priorities. Utilization of a clear conceptual model and a systematic means of measurement in this area provides important information that may be used to explore a wider perspective of family life, incorporating both positive and negative aspects, and an opportunity to improve the lives of families having a member with IDD (Isaacs, et al., 2007). The conceptualization of FQOL was built on the acknowledgment that well-functioning families serve as a societal resource and support (Isaacs et al., 2007), and that the family structure is of primary importance to the stability and functioning of human society (Brown & Brown, 2004).

**Family Quality of Life Construct and Measurement**

As a result of relationships established between family dynamics and individual QOL, and increasing familial responsibility in the care of minor and adult children with disabilities, a new priority in disabilities research emerged in family quality of life. FQOL frameworks and measures were developed to better understand experiences that led to increased family well-being and QOL for individuals with IDD. In addition, the hope was to use this information to inform policy and enhance service provision for families and individuals with IDD. While a few others have contributed to this literature, three targeted initiatives have undertaken the systematic

conceptualization and measurement of FQOL, with two primarily credited for the work.  In 1997, an international team of QOL researchers joined forces on the International Family Quality of Life Project, to eventually produce the *Family Quality of Life Survey* (*FQOLS-2006*) (Brown et al., 2006; Isaacs et al., 2007).  At about the same time, the Beach Center on Disability at University of Kansas initiated the development of the *Beach Center Family Quality of Life Scale* (*FQOLS*) (Beach Center on Disability, 2003; Hoffman et al., 2006; Park et al., 2003).  While work progressed with these groups, Aznar and Castanon (2005) advanced a similar instrument specifically designed for use with Latin American families.  This work, however, has received less attention in the literature, perhaps due to its smaller scale, somewhat later inception, and specific focus.

**International Family Quality of Life Project, *FQOLS-2006*.**  Initial efforts towards conceptualization and validation of a measurement tool incorporated consultation and discussion with a wide range of parents, other family caregivers, and professional stakeholders across various countries, including researchers from the Beach Center (Isaacs et al., 2007).  Foundational principles were incorporated from the literature on individual QOL, acknowledging that quality of life is: (1) multidimensional; (2) generally comprised of the same factors for all people, with variation in salience for some; (3) inclusive of objective and subjective elements; (4) best understood using both qualitative and quantitative methods; (5) studied for the purpose of understanding and improving the lives of individuals with IDD and their families (Isaacs et al., 2007).

With fundamental underpinnings established, the team developed a construct featuring nine domains representing areas of life in the family, along with five concepts through which to evaluate each, as described by Isaacs et al. (2007).  The domains included Health of Family,

Financial Well-Being, Family Relationships, Support from Other People, Support from Disability-Related Services, Spiritual and Cultural Beliefs, Careers and Preparing for Careers, Leisure and Enjoyment of Life, and Community and Civic Involvement.  These domains were measured by rating personal experiences across each domain, relative to the following concepts: (a) opportunities to access facets of each domain, (b) initiative taken to access opportunities, (c) attainment of opportunities, (d) satisfaction with attainment, and (e) stability of relative influence of domains over time.  A draft survey was developed incorporating these aspects and shared with parents and other researchers for feedback.  Adjustments were then made based on that input and an additional section was included to provide information on family structure and the member with disabilities.  Subjective questions were also added related to each concept across domains, with participants encouraged to elaborate on their responses.  The product resulting from this work was the Family Quality of Life Survey-2000 (*FQOLS-2000*) (Isaacs et al., 2007).

The *FQOLS-2000* was piloted for four years in Australia, Canada, Israel, South Korea, and Taiwan, with resulting data used to inform revisions of the instrument.  Adjustments included clarifying language, making allowances for more than one child with a disability in the family, standardizing Likert scales across domains, modifying response format for easier reporting, and the addition of Importance ratings, along with reorganization and renaming of domains.  The new domain framework utilized areas of Health of the Family, Financial Well-Being, Family Relationships, Support from Other People, Support from Disability-Related Services, Influence of Values, Careers and Preparing for Careers, Leisure and Recreation, and Community Interaction (Brown et al., 2003).  A shortened adaptation of this new tool was also made available, as administration was lengthy, ranging from an hour and a half to two hours.  Additionally, a general version was created for families without a family member with IDD

(Isaacs et al., 2007).  The amended version of this survey, the *FQOLS-2006*, has since been

successfully piloted, translated into twenty languages, and used in over twenty-five countries

(Samuel, Rillotta, & Brown, 2012).  The extensive degree of application demonstrates interest in

the information made available through this assessment, and the importance of continued study

in FQOL related to disabilities.  Although reliability has not been formally established, results

from different studies using this instrument have indicated promise in this area (Gardiner &

Iarocci, 2012; Isaacs et al., 2007).

**Beach Center*, FQOLS*.**  Development of the *Beach Center Family Quality of Life Scale*

was the result of extensive qualitative and quantitative research to determine primary factors

contributing to family quality of life (Hoffman et al., 2006; Park et al., 2003; Poston et al., 2003;

Summers et al., 2005).  Early work in construct development utilized literature reviews and focus

groups, as well as interviews with family members of children with disabilities, individuals with

disabilities, administrators of service agencies, and service providers.  Participants were asked to

identify factors that were "important for families to have a good life together."  Responses were

then categorized across the following ten quality of life domains:  Family Interaction, Parenting,

Daily Life, Financial Well-Being, Emotional Well-Being, Social Well-Being, Health, Physical

Environment, Advocacy, and Productivity.  The preliminary version of the *FQOLS* contained 112

items, and was administered to a sample group of 1197 individuals, representing 459 families,

across 13 geographically representative states in the United States (Park et al., 2003).

Subsequent field-testing resulted in multiple revisions of this tool, with increasingly

concise instrumentation and the development of a Spanish translation.  Using exploratory factor

analysis to reduce items and develop sub-scales, there was a reduction in length to 41 items

across five domains, which were reorganized and consolidated to consist of the following:

Family Interaction, Parenting, Emotional Well-Being, Physical/Material Well-Being, and

Disability-Related Support (Park et al. 2003).  This was followed by a newer iteration, the *Beach*

*Center FQOL Scale, version 2003*, which consisted of three sections over eleven pages,

including demographic questions about the family and member with a disability, along with

Importance and Satisfaction ratings for 25 items grouped across the five established FQOL

domain areas (Park et al. 2003).  Psychometric properties were evaluated and found to be

satisfactory, demonstrating test-retest reliability along with convergent and construct validity

(Hoffman et al., 2006; Summers et al., 2005; Wang, Turnbull, et al., 2004).  This new revision

was also translated for use among European and Mexican Spanish speakers (Samuel, Rillotta, et

al., 2012), though it was only validated through large scale study in Europe (Verdugo, Cordoba,

& Gomez, 2005).

        A final version of the *Beach Center FQOL Scale* was developed in 2005.  Confirmatory

analysis supported continued use of the 25-item scale across the same five quality of life

domains (Hoffman et al. 2006; Summers, et al. 2005), and elimination of Importance ratings.

Importance was found to be rated consistently high for most items on the survey, supporting their

validity (Cummins, 2005) and further use in psychometric evaluation (e.g. Zuna et al. 2009).

Nevertheless, the data from these ratings were not found to be useful in FQOL evaluations or

outcome measures because they did not help discriminate between important variables

(Cummins, 2005).  Demographic questions were also removed from the most current version, in

order to minimize the length of the instrument and eliminate redundancy when used concurrently

with other measures (Samuel, Rillotta, et al., 2012).  The resulting domains were Family

Interaction (relationships between family members), Parenting (activities engaged in to facilitate

the child's development), Emotional Well-Being (perceptions of stress and supports available),

Physical/Material Well-Being (meeting basic needs such as medical care and transportation), and Disability-Related Support (formal and informal at school, work, and home).  Each item is rated on a 5-point Likert scale, where 1 = *very dissatisfied*, 3 = *neither satisfied nor dissatisfied*, and 5 = *very satisfied* (Park et al., 2003; Turnbull et al., 2007).  Validity has been established by a number of studies (Hoffman et al., 2006; Summers, et al., 2005; Wang et al., 2006).

**Latin American FQOL.**  Aznar and Castanon (2005) indicated that FQOL domains established by other groups may not hold the same value for Latin American families, so they used a three phase participatory approach to develop a tool specifically for this population.  In Phase I, 56 participants described what living a life of quality meant to them, regarding their family overall, and for their member with disabilities.  Responses were categorized into domains previously developed for the *FQOLS-2000*.  Phase II required 68 respondents to rate statements based on their relevance to FQOL.  Statements with the highest mean ratings and lowest standard deviations were then categorized into six domain areas.  In Phase III, 124 family members were asked to sort statements from Phase II into the same six areas.  Statements most frequently associated with specific domains were retained for use in the final survey, which consisted of 42 items in the areas of Emotional Well-Being, Personal Strength and Development, Cohabitation Rules, Physical/Material Well-Being, Family Life, and Interpersonal and Community Relations.  Final domains and items had many similarities to those in the *FQOLS* and the *FQOLS-2006*, though the Latin American instrument framed some items in terms more aligned with individual QOL measures than family-based (e.g., have responsibilities, be seen by others as a person capable to think by his/her own).   The authors acknowledged this treatment of items, stating that for Latin American Families, "the contrast between individual QOL and family QOL is not so relevant."

*FQOLS* **vs.** *FQOLS-2006*.  For the purposes of this study, a comparison of the Beach Center *FQOLS* and the *FQOLS-2006* is pertinent to the American national sample being investigated.  Both instruments utilize rating scales across similar domains to quantify FQOL, though they are organized differently.  The *FQOLS-2006* is made up of 9 domains which are measured in terms of 5 concepts (i.e., opportunities, initiative, attainment, satisfaction, and stability).  The *FQOLS*, on the other hand, looks only at satisfaction measured across 5 domains. While these measurement initiatives are similar in theoretical foundation and framework development, they also differ in a number of ways, as identified in a comparison study by Rillotta et al. (2010).  This study found that the *FQOLS-2006* called for twice as much time to administer, taking 40 minutes while the Beach Center *FQOLS* required only 20 minutes. However, the *FQOLS-2006* allowed for family members to expand on their responses and accounted for multiple members with IDD, while the Beach Center scale did not.  On the other hand, the Beach Center items were easier to understand. This is an important to consider when utilizing self-administration methods.  Additionally, the *FQOLS-2006* was designed for international use by families of children across the life-span, including youth, adults, and seniors, both with and without disabilities.  The Beach Center *FQOLS*, on the other hand, was developed primarily for families of minor children with disabilities in the United States.  Despite these differences, research has found considerable overlap in domain content between the two scales, and suggests that they are likely to provide comparable data on FQOL (Rilotta et al., 2010; Samuel, Rillotta, et al., 2012).

**Family Quality of Life Findings**

Findings from the Beach Center *FQOLS* and the *FQOLS-2006*, along with other methodologies exploring topics related to FQOL, have been informative, demonstrating

consistent patterns across studies.  A common trend observed in this research pertains to the administration of the surveys rather than direct results. Notably, throughout FQOL investigations, there are a disproportionate number of responses contributed by mothers, substantially greater than those of fathers.  This is presumably a reflection of the common maternal role as principal care provider for the family (Brown et al., 2003).  While obtaining feedback from a more representative sample of fathers may offer a better understanding of parenting experiences relative to disabilities, there is little evidence of systematic effort to this end, to date, in the literature.  Furthermore, this may continue to be the case, as current findings are considered to be a valid representation of issues being faced by primary caregivers in relationship to the family (Brown et al., 2006).  While some variation exists between maternal and paternal ratings relative to specific FQOL domains (Wang, Turnbull, et al., 2004), at least one study suggested no difference between the two in overall satisfaction with quality of life (Wang et al., 2006).

Other trends in the FQOL literature relate directly to family experiences with disability. On the whole, there is an established tendency for families who have children with IDD to communicate lower satisfaction with FQOL than those with typically developing children (Brown, et al., 2006; Poston et al., 2003).  Parental stress, which is substantial in this population, demonstrates a clear negative correlation to satisfaction with family quality of life (Liesen, 2012; Lundy, 2011).  In order to address disability-related challenges faced by families, an individual approach is necessary to accommodate the considerable variation in priorities, preferences, and culture (Bailey et al., 1998; Breitenbach, 2004; Brown et al., 2003; Brown et al., 2006).  Distinct elements of FQOL contribute uniquely to each family's overall well-being, based on individual circumstances and values; consequently, accounting for family perspective is integral to

improving their quality of life (Brown et al., 2006).  With these details in mind, three main themes have emerged as the primary focus of most FQOL studies:  the impact of specific child characteristics, family characteristics, and support characteristics on FQOL.

**Child characteristics**.  A common topic in FQOL studies, referred to as child characteristics, explores various traits of individuals with disabilities in terms of impact on family life.  It is important to note the term 'child', in this instance, does not refer to youth, but is a reference to the parent-child relationship, which applies to both minor and adult children. Research in this area has investigated factors related to severity and nature of disability, behavioral considerations, impact of long-term residential placement, and elements related to typically occurring life transitions.

The literature examining child characteristics has yielded somewhat mixed results in how families are affected by the severity of their child's impairment.  Adaptive functioning is commonly associated with degree of disability and may therefore be an indicator of such.  In one study, adaptive functioning was identified as a significant predictor of FQOL for parents of school age children (Gardiner & Iarocci, 2015).  However, other work showed no difference in maternal stress, linked directly with quality of life ratings, based on adaptive behavior skills of their children (McStay, Trembath, Dissanayake, 2014).  Without specific regard to adaptive functioning, some early childhood research attributes lower FQOL directly to acuteness of child disability (Wang, Turnbull et al., 2004).  Hu et al. (2012) achieved outcomes consistent with these findings, but expanded their interpretation, offering possible explanations in connection to cultural context and limited family support options.

Other authors posit that such outcomes are not a product of the disabilities themselves, but rather a function of participant demographics or secondary factors often associated with

severe disabilities.  In families of young children, the negative correlation identified between

FQOL and severity of child disability may have been influenced by elements known to limit

family well-being, such as recency of diagnosis (Gardiner & Iarocci, 2012; Levison, 2015),

inadequate early childhood services (Tadema & Vlaskamp, 2010), or behavioral challenges.  A

sizeable body of evidence demonstrates a pronounced relationship between difficult child

behaviors and reduced emotional well-being as well as disability-related support for families

(e.g. Beck, Hastings, Daley, & Stevenson, 2004; Boehm, Carter, & Taylor, 2015; Brown et al.,

2006; Davis & Gavidia-Payne, 2009; Minnes et al., 2007; Schertz, Karni-Visel, Tamir, Genizi, &

Roth, 2016).  Boehm et al. (2015) also linked increased child support needs, such as those

associated with challenging behavior and severe disabilities, with decreased FQOL.

The literature also explores disability type and its impact on family quality of life.

Differentiating between conditions is not encompassed by most FQOL research, though there has

been some exploration and acknowledgment that the nature of various disabilities may indicate

unique challenges (Hastings, 2002).  For example, results indicate while some families express

being closer as a result of having a child with autism (Bayat, 2007), many experience negative

effects.  Compared to families of typically developing children, or those with Down syndrome,

families living with autism report higher rates of depression and stress with less family cohesion

and marital happiness (Dabrowska & Pisula, 2010; Ingersoll, Meyer, & Becker; 2011; Totsika,

Hastings, Emerson, Lancaster, & Berridge, 2011).  Families of children with autism are also

more likely to have unmet needs in health care, family support, and service referral (Kogan et al.,

2008).  They describe the lowest satisfaction ratings in all FQOL domains, with the exception of

Spiritual and Cultural Beliefs, which were slightly lower for families of children with Down

syndrome in one study (Brown et al., 2006).  As with severity of disability, caution should be

exercised in ascribing a causal effect to type of disability on FQOL based on correlation.  It may be that secondary factors such as challenging behavior or access to appropriate services contribute to these findings.

In addition to studying the impact of disability by type and severity, research has examined environmental influences on FQOL as a child characteristic, such as effects of long-term residential placement and transition.  Werner et al. (2009) reported augmented quality of life for families when adolescent or adult children with IDD were placed in long-term primary care outside of their parents' home, but only when the new residence was perceived to benefit the individual with disabilities.  This was the case even when the family enjoyed much of their lives together prior to the move.  Improvements to FQOL were related to increased social, vocational, and recreational freedom for those remaining in the home.  While parents expressed feelings of guilt, worry, and inadequacy, this effect diminished over time, which was considered to be a likely result of enhanced family functioning.

Transitions, such as grown children moving away from home, are customary rites of passage for the average American family, as are child advancements from preschool to kindergarten, elementary school to secondary, and high school to college or the workplace. However, families of children with disabilities often face greater challenges during these times, more than any other point in the family cycle (Gardiner & Iarocci, 2012; Minnes et al., 2007). Such progressions require flexibility to readjust to changing circumstances, and potentially necessitate additional support to cope with increasing demands.  For example, parents have expressed concern and stress over lack of information regarding inclusion support, when their child advances to public education programs from early childhood services (Davis & Gavidia-Payne, 2009).  Additionally, parents of teens and young adults moving from high school to adult

services have conveyed worries about work, community living, and social opportunities for their children.  Kraemer & Blacher (2001) found that parent concerns in this age group followed a centralized theme of having limited options available.  Specific challenges cited were overall lack of programs, long waiting lists for services, untrained support personnel (in both medical and behavioral support needs), lack of transportation, long distances to programs, and the discontinuity of services upon exiting the public school system.

**Family characteristics**.  Another subject of investigation in the FQOL literature has been family characteristics.  In this area, research has explored finances, religious practices, parental advocacy efforts, and relationships within the family unit, all in the context of their association with FQOL.  Trends have emerged from these studies, with a tendency for high FQOL ratings in the Family Relationships domain, and a positive correlation identified between financial well-being and overall satisfaction with quality of life.  Beyond this, however, results have been inconsistent, which is likely a reflection of the dramatic variability found in value systems and priorities among families (Brown et al., 2009).

Family finances have been identified as a significant predictor of FQOL, with satisfaction increasing in correspondence with income level (Brown et al., 2006; Davis & Gavidia-Payne, 2009; Schertz et al., 2016; Wang, Turnbull, et al., 2004).  As a rule, it is well-understood that families with higher socio-economic standing have greater positive outcomes than those living in poverty.  Specific to the field of disabilities study, these effects are generally attributed to families having more resources available to assist with child-specific, disability-related needs and parental coping strategies (Brown et al., 2006; Cagran, Schmidt, & Brown, 2011; Davis & Gavidia-Payne, 2009; Hu et al., 2012; Neikrug, Roth, & Judes, 2011; Petrowski, et al., 2008; Wang, Turnbull et al., 2004).  Cagran et al. (2011) additionally observed that families affected by

IDD and struggling financially report a lack of opportunity, attainment, and satisfaction relative to financial well-being, perhaps believing it impossible for their situation to improve. Nonetheless, families still tend to relate positive satisfaction with financial well-being across income levels, while at the same time reporting no money left at the end of the month.  These incongruous results highlight the subjective nature of this topic, possibly indicating the desire by families to maintain a positive focus despite adversity (Brown et al., 2003), or an exceptional level of resiliency observed more recently in the literature (Bayat, 2007).

Despite implications of the practical effect of financial well-being on access to resources, family satisfaction in this area varies widely with little regard to actual income.  Although some studies have found a positive correlation between FQOL and earnings, others suggest that family finances cease to be a significant predictor of family outcomes when formal and informal supports are taken into consideration (Davis & Gavidia-Payne, 2009).  One study found that mothers of children with disabilities report lower levels of FQOL when monetary struggle is a factor, but fathers do not (Wang, Turnbull, et al, 2004).  Furthermore, research showing the influence of informal supports, such as friends, neighbors, and extended family, negates the effect of family income as a significant predictor of FQOL altogether (Davis & Gavidia-Payne, 2009).  These results indicate that a positive perception of financial well-being is primary to FQOL, though is not necessarily a reflection of actual income.

Religious practices and beliefs also impact FQOL, though with more varied results when compared to financial well-being.  In a study utilizing open ended questions about perceived positive and negative effects of autism on family and personal lives, 45% of parent responses made some reference to God, or achieving spiritual gains as a result of having a child with autism (Bayat, 2007).  Some families have described challenges in attending religious services

and maintaining active involvement with their spiritual community, but still derived meaning

from their child's disability through their faith, referring to their child as a blessing.  Other

families spoke of their child's disability as a punishment from God, impacting FQOL in a

negative manner (Brown et al., 2003; Poston & Turnbull, 2004).  Brown et al. (2003) noted a

point of interest, that while a number of families reported some degree of acceptance from their

spiritual communities, this seldom resulted in any practical assistance.

Self-advocacy on the part of parents is another family characteristic examined in the

literature.  The influence of parental advocacy efforts toward family quality of life has been

explored in the literature with mixed results.  Overall, the impact on FQOL by such endeavors is

positively correlated with success in obtaining desired outcomes (Nachshen & Jamieson, 2000;

Wang, Mannan, Poston, Turnbull, & Summers, 2004).  According to these studies, FQOL is

enhanced when parents are able to utilize advocacy as a coping mechanism to address concerns

associated with their child's needs.  Successful negotiation of challenges enables mothers and

fathers to become more informed, educate others, obtain services, enjoy cooperative engagement

with professionals, benefit from an expanded social network, and increase feelings of confidence

and empowerment.  Conversely, FQOL is negatively impacted when desired results are not

achieved.  Under these circumstances, parents commonly express frustration with adversarial

attitudes from professionals, as they feel that the system is unnecessarily working against them.

These parents relate feelings of being in a life-long battle, draining them emotionally over time.

Such factors may cause diminished involvement due to the belief that advocacy efforts are to no

avail, resulting only in pointless legwork and increased stress.  The literature suggests that

models supporting partnerships between families and professionals are likely to produce the best

outcomes, but the relationship between advocacy and FQOL is ultimately dependent on

individual context for each family.

Individual values and traits account for a range of findings among FQOL study participants.  Notwithstanding, a common theme has become evident pertaining to familial inter-connections.  Despite considerable adversity endured by families living with disability, the domain consistently holding the highest satisfaction ratings in the FQOL research has been that Family Relationships.  While numerous studies have shown negative outcomes, such as poorer family functioning, reduced marital satisfaction, and lower sense of family coherence, the Family Relationships domain continues to be reported with the highest level of satisfaction across multiple studies (Bertelli et al., 2011; Brown et al., 2003; Cagran et al., 2011; Davis & Gavidia-Payne, 2009; Neikrug et al., 2011; Petrowski et al., 2008; Werner et al., 2009).  As with satisfaction in financial well-being, high ratings in this domain may indicate resiliency within the family, yet could also reflect an inclination to maintain a favorable outlook in the face of hardship.

**Role of Support in FQOL**.  The ability for families to obtain needed support is essential to their FQOL.  Assistance may be garnered through both formal and informal means.  Formal support consists of services usually provided through public education, government agencies, and non-profit organizations, while informal support is that which is received by virtue of friends, family, and neighbors.  Unfortunately, there is an appreciable disparity between the level of assistance families are receiving and that which they desire.  Despite broad variability in their values and circumstances, families of children with disabilities consistently rate satisfaction with support from others, both formal and informal, lowest of all FQOL domains.

Families consider the support they receive from disability-related services as an important aspect of FQOL (Tadema & Vlaskamp, 2010; Werner et al., 2009).  Further evidence supports

this as a priority, identifying professional support as one of the greatest predictors of positive

family outcomes and well-being (Davis & Gavidia-Payne, 2009; Dunst, Trivette, & Hamby,

2007; Eskow et al., 2011; Summers et al., 2007).  Parents who are most satisfied with formal

support for their children have described having cooperative relationships with professionals,

where services were provided in a respectful, coordinated, and informative manner (Davis &

Gavidia-Payne, 2009).  Yet, even when families reported receiving adequate services for their

child, they did not typically believe the same was true regarding their family (Summers et al.,

2007).

Perhaps one of the most common formal supports utilized by families is the public

education system.  Special education services often have a powerful effect on the experience of

children with disabilities and their parents (Kayama, 2010).  In a study on parent advocacy and

outcomes (Wang, Mannan, et al., 2004), numerous parents reported delays or denial of services,

which increased stress and negatively impacted FQOL.  These mothers and fathers expressed

feelings that the system was unnecessarily working against them and used metaphors related to

battle, ammunition, and war when discussing their interactions with the school.  They cited

frustrations with unqualified teachers and assistants, intimidation by school staff, illegal IEP

practices, "can't do" attitudes, lack of educational rigor, and a focus on process rather than

outcomes for their children.  On the other hand, parents felt empowered when school staff

members were collaborative and respectful, increasing FQOL.  Partnerships were viewed in a

positive light when professionals shared information about resources and provided services in a

way that reduced the need for parental advocacy.

There is some debate as to the level of responsibility incumbent upon public education to

address FQOL.  Wang, Mannan, et al., (2004) suggested there should at least be consensus that

schools should "do no harm".  A more expanded viewpoint was expressed by Kayama (2010),

stating a critical need for educational professionals to enhance parent experiences due to the

direct impact of parent care-giving and advocacy on child development.  Turnbull et al. (2003)

engaged in a full policy analysis of key federal disability statutes, maintaining that IDEA

supports efforts to address FQOL in school settings.  This study outlined and defined IDEA's

four stated goals of *equal opportunity, full participation, independent living,* and *economic self-sufficiency,* then demonstrated clear overlap with individual quality of life domains previously

identified by the QoL-SIRG.  Data analysis supported the researchers' contention that the current

focus on academic outcomes in public education is too narrow, and does not encompass the more

comprehensive QOL approach implied by IDEA.  Further, the authors asserted that academic

outcomes are a means to an end, leading to higher quality of life for all students, and not an end

unto themselves.  The study concluded that the original intent of IDEA has been largely

overlooked due to a focus on academic outcomes.  Recommendations called for policy

development incorporating IDEA's goals into the general education curriculum, in order to

address the broader intended scope of this legislation supporting efforts toward improved QOL.

In alignment with the findings from Turnbull et al. (2003), further examples indicate a

precedent that evidence-based practices in public school systems support FQOL.  Healthy

partnerships between schools and families are commonly associated with positive student

outcomes.  Epstein (1995) acknowledged a number of benefits to families, students, and

educators when parents, teachers, and other community members work in coordination.  This

study also highlighted challenges and opportunities to expanding these advantages.  While FQOL

was not addressed by name in this work, positive experiences associated with school-home

partnerships were linked to enhanced well-being, suggesting that successful collaboration may

influence quality of life for all involved.  Another strategy related to FQOL and promoted by the literature for use in public schools is Positive Behavior Support (PBS).  IDEA has codified this methodology for students in special education, and utilized it to improve building climate and behavior through school-wide application.  PBS has not only proven an effective means of increasing desired behaviors, but was founded on the goal of enriching quality of life through the development and implementation of environmental supports (Carr & Horner, 2007).  The relationship of FQOL to research-based educational methodologies illustrates that schools engaged in best practices are presently addressing quality of life issues as a matter of course.  Moreover, the Turnbull et al. (2003) policy analysis of IDEA evidences legislative support advocating procedures to enhance QOL and recommending broader implementation still.

Outside of public education, other formal supports are available for individuals with disabilities and their families, usually through government agencies and the non-profit sector.  Family-oriented services generally consist of state-funded respite or personal care aids, with resource referral, informational classes or workshops, and recreational/leisure activities, available to varying degrees by location.  As in public education, parents have cited a number of obstacles which have limited their satisfaction with the benefits offered (Brown et al., 2003; Gill & Renwick, 2007; Hammarberg et al., 2014).  Among challenges presented, families expressed frustration with the scarcity of relevant disability-related information, and with the lack of any organized manner in which to find and obtain appropriate services.  Grievances were further magnified by excessive time spent on waiting lists, which led to only a limited number of program options, where few were sufficient to meet family needs.  A shortage of accessible and suitable formal supports has created severe restrictions for families in gaining assistance fundamental to quality of life for their loved ones with disabilities and for themselves.  Critical

needs identified by parents included respite care, day programs, and family counseling, along with parent support and education.

Families and professionals alike place extensive focus on formal support as a means to improve FQOL.  While this type of assistance is critical, it is also important to acknowledge the value of personal connections, beyond those with service providers, in enhancing family satisfaction and well-being.  Social support has been linked directly to positive FQOL ratings (Liesen, 2012) through improved parental functioning and mental health, which in turn influence child adjustment (Ireys et al., 2001).  Davis and Gavidia-Payne (2009) examined the impact of various factors on the quality of life in families of young children with disabilities, and identified informal support as a significant predictor of parental well-being, associated with less depression and stress, suggesting it as a vital component of effective intervention.  Furthermore, in a review of literature by Hammarberg et al. (2014), supportive social networks for parents of children with disabilities correlated positively with improved well-being, attitudes, parent-child play opportunities, child behavior, and parent development.  Social and peer supports were suggested to be of particular importance to the well-being of families caring for children with chronic health concerns or disability, substantiating similar findings from previous studies (Ainbinder et al., 1998; Carr & Horner, 2007; Ireys et al., 2001; Kane, Wood, & Barlow, 2007; Kerr & McIntosh, 2000; McCabe, 2008; Silver et al., 1997; Singer et al., 1999; Tadema & Vlaskamp, 2010; Turnbull et al., 1999; Winch & Christoph, 1988).  Regrettably, while friends, neighbors, and relatives are willing to offer a degree of emotional comfort, families have indicated they receive little to no practical help (Brown et al., 2003; Rillotta, Kirby, Shearer, Nettelbeck, 2012).  Possible barriers to contributing tangible assistance include grieving along with parents, lack of knowledge, low comfort level, difficulty relating to unique situations, and geographical or other

physical reasons (Brown et al., 2003; Kerr & McIntosh, 2000).  Moreover, family stress has demonstrated a negative impact on obtaining social support (Liesen, 2012), which then increases stress and leads to a negative spiral.

Research has clearly demonstrated the impact of disability-related support on achieving positive outcomes for families; thus it is of great concern that, throughout the FQOL literature, the most prominent trend has been one of consistently low ratings in domains related to Disability-Related Support (Bertelli et al., 2011; Brown et al., 2003; Brown et al., 2006; Cagran et al., 2011; Ho et al., 2013; Jokinen & Brown, 2005; Neikrug et al., 2011; Petrowski et al., 2008; Rillotta et al., 2012; Samuel, Hobden, et al., 2012; Werner et al., 2009).  These results are even more striking when taking into account the contrasting variability found in ratings across all other domains.  Furthermore, parents may not take the initiative to obtain desired support as a result of health challenges in the family, limited financial resources, and troubled relationships (Rillotta et al., 2012), or possibly due to previous unsuccessful attempts, discomfort in asking for help, or perhaps the belief that help is not available (Brown et al., 2003; Nachshen & Jamieson, 2000; Wang, Mannan, et al., 2004).

Considering these circumstances, there is a clear need to link the concept of FQOL to service provision (Gill & Renwick, 2007).  High quality support systems and community resources are designed to address FQOL, build fortitude (Cox, et al., 2010), and contribute to positive outcomes in families living with disability (Davis & Gavidia-Payne, 2009; Eskow et al., 2011; Gill & Renwick, 2007).  Assisting these families in positive re-appraisal of challenging situations will further encourage favorable results through enhancement of research based coping strategies (Glidden & Natcher, 2009).  Additionally, service providers may facilitate increased levels of hope within families through not only supporting immediate practical and emotional

needs, but also by acknowledging strengths and capacity for resilience (Bayat, 2007).  Hope

correlates to the perceived ability to reach specific goals.  It has been linked with increased levels

of well-being, and identified as a factor in family resiliency in the field of disabilities (Lloyd &

Hastings, 2009).  A critical element to improving outcomes for families living with IDD is to

furnish support specific to individual family needs, targeting it directly to FQOL domains

(Schippers & von Boheemen, 2009; Summers et al., 2007).  Examples suggested for such

services include parent training/education programs, provision of respite care, day programs,

family counseling, and peer support (Dunlap & Fox, 2007; Friend, Summers, & Turnbull, 2009;

Gill & Renwick, 2007).

**Cultural Considerations**

A key element of success in improving FQOL outcomes related to disability, is the

tailoring of services to accommodate individual family values and needs (Bailey et al., 1998;

Brown et al., 2006; Gill & Renwick, 2007; Parmenter, 2004).  While this concept pertains to all

families, it may be especially germane when applied in a multicultural context.  Quality of life is

heavily influenced across cultures by a wide array of living conditions and value systems, which

foster diverse viewpoints and experiences in areas of family dynamics, perception of need,

coping strategies, and service delivery, among others (Al-Krenawi et al., 2011; Aznar &

Castañon, 2005; Breitenbach, 2004; Pichette, Berven, Menz, & La Fromboise, 1997; Rueda,

Monzo, Shapiro, Gomez, & Blacher, 2005).  At a minimum, further investigation of FQOL from

a multicultural standpoint serves a dual purpose.  It allows for a deeper contextual understanding

of well-being in families living with disability, and grants insight into the development of more

culturally relevant and appropriate service provision.

From its inception, the FQOL literature has explored family experiences with disability

throughout diverse populations, as evidenced by the efforts of the International Family Quality of Life Project (Isaacs et al., 2007), as well as that of a number of other authors. Vast differences, influenced by a number of factors, have been demonstrated in how individual cultures conceptualize and address disability-related concerns. For instance, values and practices in child rearing vary widely, whether disability is involved or not. Expectations related to child development are tied to these practices, along with the underlying belief systems (Rueda et al., 2005). Furthermore, cultural identity is likely to impact perception of needs and response to services offered (Pichette et al., 1997). The size of the community in which a family lives may impact attitudes, as those living in urban settings tend to have more autonomy and less direct influence from others in their locality than families living in small, close-knit areas; while rural communities tend to offer more inclusive group membership (Aznar & Castañon, 2005; Hu et al., 2012). Some cultures assign social stigma to disability, which may increase parent blaming and feelings of guilt, also reducing the likelihood of advocacy for needed services (Al-Krenawi et al., 2011; Hu et al., 2012; Kayama, 2010). Furthermore, in some places, families are struggling with day-to-day survival. The ability to obtain basic resources (i.e., food, shelter, safety, health care) has a dramatic impact on attitudes related to disability, as does access to educational and economic opportunities (Bailey et al., 1998; Brown et al., 2009).

Taking into account the number of cultures and societies worldwide, it is not surprising that wide variations exist in how disability is viewed and addressed. What may be unexpected, however, is that despite extensive global diversity, many families seem to value the same general elements of life and share similar difficulties, regardless of their culture (Brown et al., 2009; Cagran et al., 2011; Keith & Schalock, 2000; Renwick et al., 2000). According to Breitenbach (2004), formerly of Inclusion International, families often seek access to practical information

and advice relative to their young, advocacy in times of conflict, and protection for their children

from abuse.  Common challenges cited by parents relate to negative social attitudes, inadequate

or non-existent support, and services that undermine the best interest of families and individuals.

Rueda et al. (2005) deemed it indisputable that most parents share cross-cultural values in self-

care, positive social relationships, productive engagement, and some degree of independence for

children with or without disabilities.  They added that families also generally agree on the

importance of gaining information on disabilities, service navigation, and available support

options.  Variation in attitudes and responses to disability are a reflection of personal interest and

personality, combined with cultural influences, all overlaid upon fundamental elements of life

which are widely valued across cultures (Brown et al., 2009).  It follows that the best means of

support should encompass and address these broadly established priorities in FQOL, to inform

policy and practice in culturally relevant and responsive ways (Gardiner & Iarocci, 2012;

Parmenter, 2004; Pichette et al., 1997; Rueda et al., 2005).

In the United States, there is wide racial, cultural, and linguistic diversity, which has

continued to increase over time.  These differences contribute to challenges in service provision,

when agencies do not prioritize an understanding of cultural distinctions, or fail to provide

assistance within that context.  Barriers commonly exist related to communication styles, which

lead to difficulties in building rapport and developing positive working relationships between

families and service providers (Pichette et al., 1997; Rueda et al., 2005).  Parent advocacy

expectations within schools or other agencies conflict at times with cultural values regarding

authority (Kayama, 2010; Wang, Mannan, et al., 2004), and parents who are culturally and

linguistically diverse (CLD) may be perceived as passive or uninvolved (Wang, Mannan, et al.,

2004).  Family values might also clash with those promoted by the field and related legislation

on topics such as personal choice, friendship, independence, and equal opportunity (Rueda et al.,

2005).  In some instances, CLD families have demonstrated reticence in seeking or accepting

assistance from agencies controlled by the mainstream culture (Pichette et al., 1997).

Circumstances such as these oftentimes foster unfavorable perceptions of CLD parents by

professionals, leading to negative attitudes and poor treatment of those receiving services, in turn

causing parental dissatisfaction and lack of confidence in providers, and effectively limiting

access to services (Al-Krenawi et al., 2011; Rueda et al., 2005).

Access to culturally appropriate and relevant services is imperative to facilitate the

broadest possible benefit for all members of our society.  While the literature continues to

explore the priorities and practices of CLD families, caution must be exercised not to assume the

universality of specific traits or making inferences about individuals based on culture, race, or

ethnicity.  Culture-based beliefs are dynamic in nature, and not necessarily held by all members

of a given group (Rueda et al., 2005).  Likewise, groups exist which may be generalized as

sharing a common culture, when in actuality they do not.  Native Americans, for example, are

routinely referred to as if they were a single entity, though they are in fact made up of many

unique tribes, and too heterogeneous to be accurately defined by common expectations on a

cultural basis (Pichette et al., 2001).  So, while it is critical to build cultural responsiveness into

disability service models, it is equally important to avoid over-generalization of cultural

expectations.

Although some insight has been gained into cross-cultural experiences with FQOL in

families living with disability, continued efforts are necessary to understand and address the

needs of these families, especially in geographic areas beyond North America and Western

Europe (Al-Krenawi et al., 2011; Azner & Castañon, 2005; Gine et al., 2013).  It is clear that

culturally responsive services must utilize a family centered, life-span approach, and that they

require a positive working partnership between families and professionals to be effective

(Breitenbach, 2004).  The measurement of FQOL is necessarily dependent on subjective opinions

and viewpoints, where individual perceptions of circumstances may have as much effect on

family function as the circumstances themselves.  In order to better understand and meet the

needs of families living with disability in the United States and across the globe, researchers

continue to appeal for further examination of FQOL across cultural and political boundaries.

**Parent-Peer Mentoring Support**

In an effort to enhance quality of life for families of children with disabilities, services

which respect unique family value systems and take into account other findings from the FQOL

literature should be provided.  One model well-suited to accomplishing this goal is parent-to-

parent peer support, which has been established as an effective means to assist families of

children with disabilities since the late 1980s (Winch & Christoph, 1988).  The Parent to Parent

movement in the United States has been described as "likely to have considerable value" to

parents of individuals with disabilities, in managing day-to-day stress and challenges (Hastings

& Beck, 2004).  These programs typically match trained, experienced, mentor parents (usually

volunteers) with families seeking assistance.  Pairings are based on priorities identified by

inquiring parents, and consideration of shared child and family characteristics with the peer

mentor.  Common experiences between the families are the foundation for this relationship,

enhancing the likelihood of connection and responsiveness to concerns.  This type of support

originated in the field of Children's Health, to aid mothers and fathers of children with serious

medical concerns (Ainbinder, et al., 1998), and was founded on the philosophy that parents of

children with special needs are uniquely qualified to help each other (Singer et al., 1999).   Since

its inception, parent-to-parent support has expanded widely, incorporating groups focused on specific conditions (McCabe, 2008), and demonstrating benefits for families of typically developing, healthy children as well as those with disabilities or special health care needs (McConnell et al., 2012).

An early descriptive study explored the benefits of non-categorical parent-to-parent support initiated at the University of Virginia Children's Medical Center, where the only commonality between families was having a child in the hospital (Winch & Christoph, 1988). Parents in this study found value in opportunities for group interaction which provided a space for sharing and problem solving.  In such groups, they were able to share feelings and experiences, give and receive information about the hospital, discuss and understand their own needs separate from their child's, assess individual family needs, and reduce feelings of isolation. This model was advanced as a cost-effective means to support families, with positive impact evidenced through improved parental advocacy, communication, and awareness of the system. Group networking by participants was noted to extend beyond original weekly meetings investigated by the study, leading to parent-developed, community-based out-patient groups. The expansion of the group outside of its original context attests to the social validity of inter-family connections for these parents, and the potential for positive outcomes through the development of parent-to-parent support groups.

Subsequent studies have upheld the findings from Winch & Christoph (1988) and detailed an extensive record of added benefits to be gained from parent peer support models, applying to a range of family circumstances, and addressing social, emotional, and practical considerations.  In the social arena, families of children with and without disabilities or special health care needs have reported decreased feelings of isolation, and increased moral support,

with an added sense of acceptance and normality not found elsewhere, as a result of parent peer support (Ainbinder et al., 1998; Hammarberg et al., 2014; Kane et al., 2007; Kerr & McIntosh, 2000; McCabe, 2008; McConnell et al., 2012; Winch & Christoph, 1988).  Relationships with parent peers have been characterized as more equal and less discriminatory than those experienced in general society (McCabe, 2008).  Furthermore, mothers and fathers have placed great value in "finding others out there who understand" (Singer et al., 1999).  On an emotional level, disability-related parent-to-parent support has led to a sense of encouragement (McCabe, 2008) and empowerment (Singer et al., 1999).  Additionally, it has helped resolve feelings of confusion, guilt, anxiety, anger, and depression (Kane et al., 2007; Kerr & McIntosh, 2000), and aided in developing acceptance of disability in the family (Ainbinder et al., 1998; Singer et al., 1999).  Further benefits include the buffering of stress and improved coping (Ainbinder et al., 1998; Kane et al., 2007; Kerr & McIntosh, 2000; Silver, Ireys, Bauman, & Stein, 1997; Singer et al., 1999; Tadema & Vlaskamp, 2010; Turnbull, Blue-Banning, Turbiville, & Park, 1999), which in turn, contribute to overall well-being (Hammarberg et al., 2014; Ireys et al., 2001; Tadema & Vlaskamp, 2010).  Practical assistance has also been a highly regarded outcome of parent-to-parent peer support, through acquisition of information (Hammarberg et al., 2014; McCabe, 2008; Winch & Christoph, 1988), problem solving for every-day needs (Ainbinder et al., 1998; Kerr & McIntosh, 2000; Singer et al., 1999; Winch & Christoph, 1988), and guidance in accessing and navigating disability service systems (Hammarberg et al., 2014; Winch & Christoph, 1988).  Parents reported that peer support offered experiential learning that was not available from other sources (Kerr & McIntosh, 2000), and at times this connection was valued over coinciding services provided for their children (McCabe, 2008).

An added value of this approach was found in its reciprocal nature, with benefit derived

from both giving and receiving assistance (Ainbinder et al., 1998).  Parents have recounted numerous positive outcomes obtained through accessing peer support, though over time they reported shifting roles towards a more supportive position relative to others.  This change allowed experienced parents to function as role models (McCabe, 2008), providing an example of success, confidence, and challenges overcome.  In addition, parents finding themselves in supportive roles described a sense of closure and of having come full circle, identifying this as a final step and an integral part of the parent peer support process (Ainbinder, et al., 1998; Kerr & McIntosh, 2000).

While there are a number of benefits available through parent-to-parent support, barriers still exist to participation.  In a recent study, Hammarberg et al. (2014) summarized factors that influence the successes and failures of these programs in meeting family needs.   Challenges which limited participation often related to themes of group heterogeneity in areas such as level of comfort confiding in others, recency of diagnosis, emotional processing, socio-economic standing, severity of child's disability, and family problems in marriage, finance, or mental health.  Some parents did not perceive a benefit to their child, or no longer felt the need to attend; others described a lack of group cohesiveness and feeling unsupported.  Parents also felt dissatisfied when funding was insufficient to cover year-around programming.  Inconvenient meeting times and travel distance were barriers for some, and additional challenges were noted in accessibility for low-income and CLD families.

The vast majority of parents, however, found participation worthwhile despite differing backgrounds and values.  Even when they were no longer attending the program, mothers and fathers affirmed gaining social support, a sense of belonging, and useful skills in navigating disability services.  Positive family experiences were associated with groups offering relevant

information, opportunities for discussion and interaction, meaningful activities, appropriate

group facilitation, and connections to community resources which provided funds and practical

assistance.  Many parents expressed interest in connecting with others in similar circumstances

when given the opportunity (Kerr & McIntosh, 2000; McConnell et al., 2012), showing

enthusiasm and an eagerness to help each other (McCabe, 2008).  Participants considered mentor

parents helpful when they shared comparable experiences and were willing to both give and

receive support.  Additionally, while similarities among members contributed to positive

outcomes in some groups (Ainbinder et al., 1998), socio-economic and cultural diversity was

noted with appreciation in others (Hammarberg et al, 2014).

Parent-to-parent peer support is a model which has the potential to make a meaningful

contribution to FQOL, demonstrating clear positive outcomes for parents, families, and

individuals with disabilities.  Philosophically, it operates in alignment with evidence-based

practices related to person-centered planning and family-based support, which are grounded in

attachment, ecological, and family systems theory, and are central to current best practice in

special education and other disability-related services.  From a pragmatic standpoint, parent-

based social networks grant access to meaningful knowledge and information pertinent to

specific needs and experiences.  These groups also equip families with social and emotional

supports shown to reduce negative outcomes, such as depression and isolation, while fostering

confidence, acceptance, and overall well-being.  Because such programs tend to rely heavily on

volunteers for implementation, they also offer a cost-effective mechanism in which to address a

broad array of family needs.  Groups may be successful with a degree of heterogeneity, or be

engineered for responsiveness to particular demographics in a community.  Hence, parent-to-

parent networks function as a gateway to both formal and informal assistance for an array of

family needs, with the capacity to impact FQOL by reducing the challenges associated with obtaining needed support.  Parent peer mentoring embodies the core values driving advocacy efforts in the field of disability support today, such as empowerment, acceptance, and self-determination.  Through this model, we have the potential to mitigate the single most pervasive challenge to families in the FQOL literature by improving access to support from others.

**CHAPTER THREE**

**Method**

**Procedures**

A survey research design was used for this descriptive study.  The survey was adapted

from print to an electric online format using WebQ through Catalyst Web Tools.  Data was then

exported to SPSS 19 for analysis.

**Recruitment**.  The target population for this study was a national sample of parents or

guardians who were the primary caregivers of individuals with disabilities living at home.  There

was no limit placed on type of disability or age of the family member under consideration, in

order to achieve the broadest possible sample of family experiences.  Information about this

study, including a description of the research and link to the survey, was provided to the Parent to

Parent program of the Arc of Washington for large scale electronic dissemination to contact lists

via email and social media.  These contacts included individuals, families, schools, agencies, and

other Parent to Parent and Arc programs across the country, all of whom were encouraged to

forward the link to others who may be interested in participation.  While distribution originated

with the Parent to Parent program, it was anticipated that as the survey link was shared, it would

allow for the study to be shared among a wide range of families nationwide, including many who

were not associated with Parent to Parent or The Arc.  Parent to Parent sent out further reminders

for participation on two separate occasions once the survey was active, in order to boost response

rate.  Participation was determined through self-selection and limited to one response per

household, by parents or guardians aged 21 years or older.

Prior to accessing the survey, respondents were presented, via online link, with a

description of the study and its purpose, as well as parameters for participation (i.e. age 21+,

parent/guardian of minor or adult child with a disability living in the home, no more than one response per household).  Informed consent was indicated by clicking an electronic button, which then linked to the survey.  Those who chose not to participate were able to exit at any time.  No personally identifiable information was requested and all data was managed through secure systems, ensuring confidentiality.  Participants were asked to respond to some survey items regarding their minor or adult child with disabilities.  If they had more than one child fitting that description, they were asked to respond while thinking of the one who had the greatest impact on family life.

  **Instrument.**  This study utilized the Family Quality of Life Scale, developed by the Beach Center on Disability at the University of Kansas (Hoffman et al., 2006).  The Beach Center instrument was deemed the best fit for the purposes of this study when compared to the *FQOLS-2006*, due to its shorter length and ease in self-administration, as indicated by Rillotta et al. (2010).  Some minor adaptations were made in order to expand the scope of this measure from use by parents of minor children with disabilities, for whom it was originally designed, to those of adult children as well.  These included modifications of some wording to differentiate between experiences of children and adult family members with disabilities, as detailed below.  Furthermore, two new questions were added pertaining to family participation and disability-related support in the community setting, which were not addressed elsewhere in the *FQOLS*.  Also added were 11 demographic questions, and 3 items related to participation in parent-to-parent groups and other family support programs, followed by a section for comments.  For a hard copy of the survey, see Appendix.

  ***Family quality of life scale.***  The Beach Center *FQOLS* is a 25-item self-report questionnaire, measuring parent satisfaction ratings across five domains associated with Family

Quality of Life. Each item is rated on a 5-point Likert scale, where 1 = very dissatisfied, 3 = neither satisfied nor dissatisfied, and 5 = very satisfied. The domains assessed include Family Interaction (FI), Parenting (P), Emotional Well-Being (EWB), Physical/Material Well-Being (PMWB), and Disability-Related Support (DRS). The Family Interaction domain consists of items related to families spending time together, including solving problems and communicating (e.g., My family enjoys spending time together.). The Parenting domain refers to teaching children to make good decisions, be independent, and get along with others (e.g., My family members teach the children to be independent.). Emotional Well-Being rates topics related to the family having the supports needed to cope with everyday life (e.g., My family has the support we need to relieve stress.). Physical/Material Well-Being examines satisfaction with financial resources to provide for the family (e.g., My family has a way to take care of expenses.). Disability-Related Support explores satisfaction with services the child receives (e.g., My child has support to accomplish goals at school or at the workplace.).

Evaluation of the FQOL Scale's psychometric properties has established high convergent validity, internal consistency, and test-retest reliability (Hoffman et al., 2006; Isaacs et al., 2007; Summers et al., 2005). In addition, the overall FQOL model has demonstrated an excellent fit [c2 (5) = 3.41, P = 0.63, CFI = 1.00, RMSEA = 0.00, and a Chronbach's alpha of 0.88, with the following for individual domains: Family Interaction (a = 0.90), Parenting (a = 0.86), Emotional Well-Being (a = 0.84), Physical/ Material Well-Being (a = 0.74), and Disability-Related Support (a = 0.85) (Hoffman et al., 2006). While adaptations to this tool may have impacted its validity to some degree, efforts were made to maintain as much integrity as possible from the original instrument, while still gathering important new data.

The Beach Center *FQOLS* was developed for use by parents of children with disabilities

(Rillotta et al, 2010).  For the purposes of this study, the instrument's scope was expanded to incorporate data from parents of adults with disabilities as well, with select items edited for improved suitability to this demographic and offered to respondents indicating adult children with disabilities living in the home.  Original phrasing of items was largely applicable with regards to both minor and adult children, with the exception of some text in the Parenting domain.  Wording of items in this area was altered to reflect variations between child and adult characteristics and experiences, but was maintained to the greatest extent possible, to minimize impact on assessment validity.  For example, regarding children, one item read, "My family helps them learn independence," while the version for parents of adults was edited to say, "My family helps them to increase independence."  This phrasing was changed in an effort to avoid infantilizing adults with disabilities, as the term "learn" could be associated more with younger children and insinuate having not yet learned, while the word "increase" connotes a previous level of acquisition one may typically associate with adulthood due to previous experience.  The terms "adult" and "children" were also removed from two items to minimize age differentiation between adults with disabilities and other adults in the family.  Additionally, some items were modified to reflect age-based experiences, shifting childhood school-based terminology (i.e. schoolwork, teacher) to phrasing more relevant in adult life (i.e. activities, caregivers), and accounting for the possibility that families with adult children may no longer be caring for minor children living in the household.  For the purposes of analysis, adult-oriented items were matched with their child-oriented counterparts, and scored together under the same item.

As participants moved through the survey, skip logic was used to direct them to child or adult items for the Parenting domain.  Respondents indicating that they had minor children were directed to the original child-oriented *FQOLS* Parenting domain items.  These items referred to

all children, not only those with disabilities, as all require parenting support in the areas

measured by this domain.  Participants having adult children with disabilities were able to skip

the child-oriented questions when not applicable, moving instead to those edited for adults.

While these questions were directed to all adult family members with disabilities in the home, it

is likely that responses in this section applied mostly to individuals, in contrast to the child-

oriented questions, as it is more likely for a family to have multiple children in the home than

multiple adults with disabilities.  Furthermore, because child-oriented items addressed all

children in the home, and adult-oriented items were specific to those with disabilities, in cases

where families had an adult child with disabilities along with minor siblings, (n = 44),

participants responded to both sets of questions.

     In addition to modifications in the Parenting domain, two new questions were included

along with standard *FQOLS* items regarding family participation and disability-related support in

the community setting.  The incorporation of this information was considered meaningful, as

community involvement is associated with enhanced quality of life for individuals with

disabilities (Schalock, 2004), and likely impacts FQOL as well (Hall, 2016).  Furthermore, high

unemployment rates (74-93% depending on type of disability) continue to plague adults with

disabilities (U.S. Department of Labor, Bureau of Labor Statistics, 2016; Erickson, Lee, & von

Schraeder, 2016), leaving the general community as their primary context for experiences

outside of the home.  In order to address the importance of community involvement for families

of children with disabilities, an additional item in the domain of Emotional Well-Being asked

families to rate their ability to enjoy activities in the community together.  Furthermore, under

Disability-Related Support, existing questions about available support to accomplish goals at

school, work, or home were expanded to also address support in the community setting.

**Demographics, parent support, and comments.**  In addition to items related to quality of life, participants responded to questions regarding demographics and participation in parent support programs in order to identify possible relationships between these factors and FQOL. Along with typical items regarding age, gender, ethnicity, etc., further inquiries were made regarding the nature of child disability, time since diagnosis, and level of support needed for success in school, work, home, and the community.  Respondents were also asked if the family had experienced a death, divorce, or other traumatic event over the past 12 months, as such circumstances would be likely to impact FQOL (Gardiner & Iarocci, 2012).  Items regarding parent support specifically addressed participation in parent mentoring programs, frequency of attendance, and satisfaction with services.  A menu of other disability-related activities and service options was provided, and participants were asked to identify those they had used and found helpful.  Upon completion of all other items, a final space was provided for general comments.  The *FQOLS* was not designed to incorporate qualitative data, though this is an element of the *FQOLS-2006* which parents greatly valued (Rillotta et al., 2010).  While a full qualitative analysis of this section is beyond the scope of this study, it was considered of value to allow the opportunity for participants to voice that which they chose to share, to perhaps provide further insight into their experiences.

## CHAPTER FOUR

## Results

### Participants

Participants consisted of 283 parents and primary caregivers of minor or adult children with a disability living in the home. Table 1 presents demographic data for these families. Of those surveyed, 89% were parents, with 10% of the remaining caregivers identifying as other family members, and 1% as non-related caregivers or other. In this sample, 93% of respondents identified as female, 7% as male, and one (< 1%) as other. Over half of the participants were ranged in age between 31 – 50 (65%), with approximately 8% between 21-30 years, 17% aged 51-60, and 10% at 61 years or older. Age data was deemed inaccurate in one instance (< 1%) because reported age range for the parent (< 21) overlapped that of the child (19-21). Upon closer examination of responses by this participant, (i.e., identifying as being over age 21 for participation in the study, indicating 15+ years since child's diagnosis, responding to items selected for those with an adult child with disabilities), it appeared that the parent mistakenly reported the child's age as his own. There was no evidence suggesting the child's information was incorrect, therefore parent age data for this record was presumed faulty and excluded from analysis. In terms of racial/ethnic make-up, respondents were primarily Caucasian (87%), though some were also of mixed race (7%), Hispanic (2%), Asian (1%), African American (1%), Native American (1%), and Pacific Islander (< 1%). Data related to residence and income, for 274 responses, was collected by means of zip code analysis via online mapping software through www.esri.com. The remaining 9 records were excluded because they did not reference numbers which were identified with actual zip codes. These data are presented in Table 2. The majority of families (59%) resided in the state of Washington, where recruitment originated, with

representation across 26 additional states throughout the country.  Respondents lived in a variety

of community types, with 9% living in desert areas, 46% in rural areas, 37% in the suburbs, and

7% in small cities.  None of the study participants lived in urban or metropolitan areas with a

population greater than 25,000 per square mile.  Median annual income for families by zip code

was less than $32,000 for 2%, and ranged between $32,000-$47,000 for 22%, $47,000-$67,000

for 47%, $67,000-$99,000 for 26%, and $99,000-$200,000 for 3%.  Over the past 12 months,

75% of respondents reported a divorce, death, or other traumatic event in the immediate family.

Table 1

*Respondent Demographics*

| Variables for Individuals | $n$ ($N = 283$) | % ($N = 283$) |
|---|---|---|
| Relationship to family member with disability | | |
| Parent | 252 | 89 |
| Grandparent | 5 | 2 |
| Sibling | 4 | 1 |
| Other relative | 19 | 7 |
| Non-related guardian | 1 | <1 |
| Other | 2 | 1 |
| Gender | | |
| Female | 262 | 93 |
| Male | 20 | 7 |
| Other | 1 | <1 |
| Ethnicity | | |
| African American | 2 | 1 |
| Asian | 3 | 1 |
| Caucasian | 247 | 87 |

| | | |
|---|---|---|
| Hispanic | 6 | 2 |
| Native American | 3 | 1 |
| Pacific Islander | 1 | <1 |
| Two or more races | 21 | 7 |
| Age (*N* = 282) | | |
| 21-30 | 23 | 8 |
| 31-40 | 82 | 29 |
| 41-50 | 102 | 36 |
| 51-60 | 48 | 17 |
| 61+ | 28 | 10 |
| Trauma in past 12 months | 212 | 75 |

Table 2

*Respondent Demographics by Zip Code*

| Variables for individuals | *n* (*N* = 274) | % (*N* = 274) |
|---|---|---|
| Community Type | | |
| Desert (100 or less) | 26 | 9 |
| Rural (101-1,000) | 127 | 46 |
| Suburban (1,001-5,000) | 101 | 37 |
| City/town (5,001-25,000) | 20 | 7 |
| Annual median income | | |
| $32,000 or less | 6 | 2 |
| $32,001-$47,000 | 59 | 22 |
| $47,001-$67,000 | 129 | 47 |
| $67,001-$99,000 | 72 | 26 |
| $99,001-$200,000 | 8 | 3 |

State of residence

| | | |
|---|---|---|
| Alabama | 3 | 1 |
| Arkansas | 1 | <1 |
| Arizona | 4 | 1 |
| California | 13 | 5 |
| Colorado | 1 | <1 |
| Florida | 1 | <1 |
| Hawaii | 1 | <1 |
| Idaho | 2 | 1 |
| Illinois | 2 | 1 |
| Indiana | 2 | 1 |
| Kansas | 1 | 1 |
| Maryland | 3 | 1 |
| Michigan | 11 | 4 |
| Minnesota | 3 | 1 |
| Missouri | 4 | 1 |
| North Carolina | 8 | 3 |
| New Mexico | 2 | 1 |
| New York | 3 | 1 |
| Ohio | 4 | 1 |
| Oregon | 2 | 1 |
| Pennsylvania | 13 | 5 |
| South Carolina | 2 | 1 |
| Tennessee | 6 | 2 |
| Texas | 11 | 4 |
| Utah | 1 | <1 |
| Virginia | 8 | 3 |
| Washington | 162 | 59 |

Family members with disabilities, who were reported on by respondents in this study, consisted of 186 minors and 97 adults, with 12% aged 5 years or younger, 24% between 6-10 years, 18% aged 11-14, 13% at 15-18 years, 10% between 19-21, 14% aged 22-35 years, 5% between 36-55, and 5% at 55 years or older.  Demographic information for these individuals regarding age, gender, and time since diagnosis is presented in Table 3.  Gender of minor and adult children was reported as 64% male, 35% female, and 1% other.  Time since diagnosis was less than one year for 5% of these individuals, 2-4 years for 26%, 5-10 years for 29%, 11-15 years for 13%, and 15 or more years for 28%.  Respondents were offered seven categories with which to best describe their loved ones' disabilities, as well as a choice for "Other" which included a fill-in option.  When asked to select all that apply, 45% identified autism, 32% emotional/behavioral challenges, 39% IDD, 27% learning disabilities (LD), 31% physical or health impairments, 33% speech and language difficulties, 17% vision or hearing impairments, and 19% other.  Of those identified with IDD, nearly half (48%) were also said to have LD, demonstrating a great degree of overlap and likely reflecting varying definitions of these categories.  Furthermore, the high percentage of participants who selected "other" necessitated further exploration related to the fill-in portion of these responses.

Table 3

*Demographics for Minors and Adults with Disabilities*

| Variables for individuals | $n$ ($N = 283$) | % ($N = 283$) |
|---|---|---|
| Age | | |
| 0-5 | 33 | 12 |
| 6-10 | 67 | 24 |
| 11-14 | 50 | 18 |

| | | |
|---|---|---|
| 15-18 | 36 | 13 |
| 19-21 | 27 | 10 |
| 22-35 | 41 | 14 |
| 36-55 | 14 | 5 |
| 55+ | 15 | 6 |
| Gender | | |
| Female | 98 | 35 |
| Male | 182 | 64 |
| Other | 3 | 1 |
| Years since diagnosis | | |
| <1 | 13 | 5 |
| 1-4 | 73 | 26 |
| 5-10 | 82 | 29 |
| 11-15 | 37 | 13 |
| 15+ | 78 | 28 |

Of the participants who chose "other" as a descriptor for their family member's disability, there were 29 (55%) who named or described conditions which were potentially encompassed by other categories offered, but without selecting those options.  Of these, 15 (28%) did not select any of the primary options available.  From the overall group who selected "other", 10 participants identified diagnoses associated with intellectual and developmental disabilities (i.e., Lesch-Nyhan syndrome, Down syndrome, 22q11.2 deletion syndrome, Fragile X), or used the terms "developmental delay" and "global delays", all without selecting IDD as a description of their child's disability.  Another 12 respondents described mental health conditions linked with emotional and behavioral challenges (e.g., Alzheimer's, Post-Traumatic Stress Disorder, bi-polar disorder), but did not check the box for emotional/behavioral disability.  Information from 14

families indicated experiences with cerebral palsy, hemiplegia, tumors, seizures, sleeping disorders, or amputation, but none selected physical/health impairments as a way to describe their child.  One parent identified hearing loss under the category of "other", but did not choose the available option of vision/hearing impairment.  In addition, three cases of traumatic brain injury and one case of fetal alcohol syndrome were listed under "other", with no other categories selected, despite the fact that behavioral and learning difficulties are commonly associated with these conditions and respondents indicated support needs for these loved ones in other sections of the survey.

A number of other participants *(n* = 16) appeared to use the fill-in section of the "other" selection to name the conditions directly related to disability types which they had already identified through available options in the survey instrument.  The results for 10 (19%) respondents describing children as having IDD or physical/health impairments used this space to name diagnoses such as brain injury, myotonic dystrophy, cerebellar hypoplasia, hydranencephaly, Ehlers-Danlos syndrome, and Down syndrome, or to use descriptive phrases such as "mild retardation", "abnormal nervous system", and "survivor of massive stroke". Further, there were 6 (11%) participants who selected the category of emotional/behavioral disability and responded in a similar manner, naming diagnoses such as bipolar, attention deficit hyperactivity disorder, and oppositional defiant disorder, or used descriptive terms such as "mental health" and "born meth positive".  Some families checked "other" but did not comment further *(n* = 2).  Of those who provided no further comment after checking "other", one respondent had checked all of the available options, and another selected emotional/behavioral challenges and learning disabilities.

For purposes of analysis, data for those who selected a combination of IDD and LD to

describe their family member with disabilities, as well as some who utilized the "other" option were re-coded.  In response selections including both IDD and LD, the category of LD was removed to more clearly reflect the nature of disability experienced by the family member under consideration.  These categories were meant to be differentiated as they are in special education, where LD is characterized by a significant discrepancy between cognitive ability and academic performance in a given area, and IDD is associated with more pervasive delays.  Further examination of the results identifying family members as having both IDD and LD supported the conclusion that IDD was the most appropriate description between the two categories, based on reported levels of support needs from other survey items, and anecdotal comments included at the end of the survey.  For those who selected "other" to describe their family member's disability, two different actions were taken.  In cases where comments indicated disability categories which had already been selected (e.g., IDD selected with comment under "other" stating "mild retardation"), the option of "other" was dropped to eliminate redundancy.  For responses indicating "other", without clear corresponding disability types selected, categories were assigned based on the information provided.  Various conditions commonly associated with IDD (i.e., developmental disability, global delay, Fragile X syndrome, Lesch-Nyhan syndrome, Down syndrome, 22q11.2 deletion syndrome) were placed under that heading.  Descriptions of physical disabilities, brain injury, tumors, seizures, amputation, cerebral palsy (CP), Alzheimer's, dementia, and fetal alcohol syndrome were categorized as physical or health impairments, and "hearing loss" was added under vision and/or hearing disability.  All remaining write-in responses under "other" remained in that category ($n = 7$). Table 4 provides information on disability categories reported by respondents alongside re-coded data used for analysis.

Table 4

*Disability Categories*

|  | Reported (*N* = 283) | | Re-coded (*N* = 283) | |
|---|---|---|---|---|
|  | *n* | % | *n* | % |
| Autism | 126 | 45 | 126 | 45 |
| Emotional/behavioral disability | 91 | 32 | 91 | 32 |
| Intellectual/developmental disability | 111 | 39 | 120 | 42 |
| Learning disability | 78 | 28 | 25 | 9 |
| Physical/health impairment | 89 | 31 | 102 | 36 |
| Speech/language disability | 93 | 33 | 93 | 33 |
| Vision and/or hearing disability | 47 | 17 | 48 | 17 |
| Other | 53 | 19 | 7 | 2 |

**Q1:  What is the FQOL of families, identified by parents/guardians of minor and adult children with disabilities living at home in the United States?**

Descriptive statistics were conducted to answer the first research question for this study. This question sought to determine overall FQOL for a national sample of American families.  To address this, parent satisfaction ratings were summarized by calculating the mean score for each item, then taking the mean of overall item scores to establish ratings for each domain.  In the Parenting domain, in cases where respondents reported on both child and adult-oriented items, composite scores were created from matched items in order to have a single item score for comparison with other data.  Final FQOL scores, which are presented by bar graph in Figure 1, were established by taking the mean of domain ratings.  Results by item and domain are displayed in Table 5.

Figure 1. *Frequency of Overall FQOL Scores*
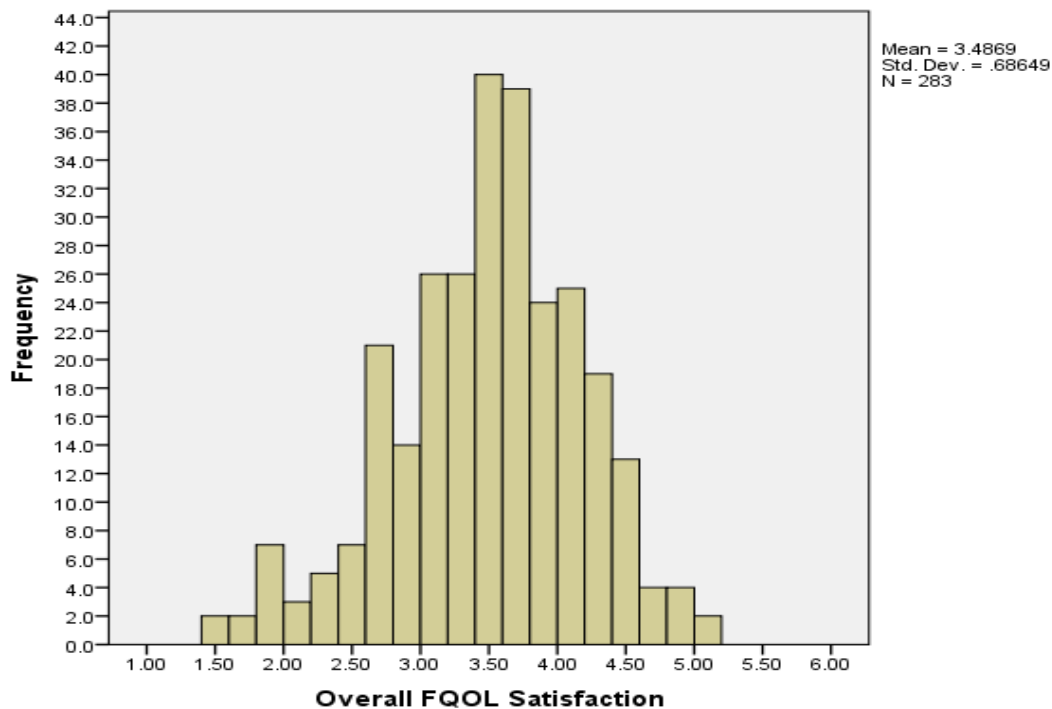


Overall, parents and primary caregivers indicated being between neutral and satisfied (*M* = 3.49, *SD* = 0.69) with their family quality of life. Over 78% (*n* = 222) of the participants had a total FQOL score of 3 or above.  Physical/Material Well-Being (PMWB) was the highest rated domain (*M* = 3.88, *SD* = 1.03), followed by Family Interaction (*M* = 3.78, *SD* = 0.85), Parenting (*M* = 3.78, *SD* = 1.03), and Disability-Related Support (*M* = 3.08, *SD* = 0.89).  The lowest ratings were in the area of Emotional Well-Being (*M* = 2.92, *SD* = 0.96).

**Physical/material well-being (PMWB) domain.** In the Physical/Material Well-Being domain, at least 70% of participants expressed satisfaction (i.e., satisfied or very satisfied) on 4 out of 5 items, although only about half (51%) said they were satisfied with their ability to take care of family expenses.  Satisfaction was highest with meeting transportation needs (83%) and feeling safe at home, school, and in the neighborhood (80%). Highest ratings of dissatisfaction (i.e., dissatisfied or very dissatisfied) in this domain were for items related to taking care of

family expenses (31%) and obtaining dental care for the family (20%).  Dissatisfaction was rated much lower (9-11%) on other items in this domain.

**Family interaction (FI) domain**.  In the Family Interaction domain, the item "My family members show that they love and care for each other" had both the highest number of respondents expressing satisfaction (86%) and the least number indicating dissatisfaction (7%).  In addition, 75% were satisfied that their family enjoyed spending time together.  Satisfaction in all other items ranged between 59-69%.  Dissatisfaction expressed for 5 out of 6 items was between 11-16%.

**Parenting (P) domain.** The Parenting domain had the most consistent ratings in both satisfaction (72-75%) and dissatisfaction (7-11%) when compared to other domains, with no more than a 4% difference in 5 out of the 6 items.  The single item rating outside of these ranges was "My family has time to take care of the individual needs of every child/their needs", which demonstrated the least amount of satisfaction (58%) and most amount of dissatisfaction (18%) for this domain.

**Disability-related support (DRS) domain**. In Disability-Related Support, approximately half of the respondents were satisfied with support for their minor and adult children to accomplish goals at home (55%), and at school or work (49%).  However, support to make friends and meet goals in the community was rated much lower (34-36%), and the highest levels of dissatisfaction in this domain were with support making friends (44%).  Relationships with service providers garnered the lowest satisfaction (30%), as well as the largest percentage of neutral responses (40%) of any other item on the survey.

**Emotional well-being (EWB) domain.** In the domain of Emotional Well-Being, 4 out of 5 items were rated between 31-39% for satisfaction, and 39-47% for dissatisfaction.  The most

satisfaction (44%) was indicated for the item "My family members have friends or others who provide support". The two highest rated items for dissatisfaction (both 47%) were "My family has the support we need to relieve stress" and "My family has outside help available to us to take care of special needs of all family members".

Table 5

*Parent/Guardian Responses on FQOLS with Adapted Items*

| Domain/Item | Percentage of responses N = 283 | | | | | |
| --- | --- | --- | --- | --- | --- | --- |
| | 1 | 2 | 3 | 4 | 5 | *M (SD)* |
| **Family interaction** | | | | | | **3.78 (0.85)** |
| My family enjoys spending time together. | 2.5 | 8.5 | 14.1 | 45.6 | 29.3 | 3.91 (1.00) |
| My family members talk openly with each other. | 1.4 | 14.5 | 16.3 | 39.6 | 28.3 | 3.79 (1.05) |
| My family solves problems together. | 4.9 | 11.3 | 21.2 | 47.7 | 14.8 | 3.56 (1.03) |
| My family members support each other to accomplish goals. | 3.2 | 12.0 | 15.9 | 50.5 | 18.4 | 3.69 (1.01) |
| My family members show that they love and care for each other. | 2.1 | 4.9 | 7.4 | 43.5 | 42.0 | 4.18 (0.92) |
| My family is able to handle life's ups and downs. | 3.2 | 10.6 | 27.9 | 45.6 | 12.7 | 3.54 (0.95) |
| **Emotional well-being** | | | | | | **2.92 (0.96)** |
| My family has the support we need to relieve stress. | 16.6 | 29.3 | 22.6 | 24.7 | 6.7 | 2.76 (1.19) |
| My family members have friends or others who provide support. | 10.2 | 23.7 | 22.6 | 30.4 | 13.1 | 3.12 (1.21) |
| My family members have some time to pursue their own interests. | 12.7 | 27.9 | 22.3 | 28.6 | 8.5 | 2.92 (1.19) |

| | | | | | |
|---|---|---|---|---|---|
| My family has outside help available to us to take care of special needs of all family members. | 20.5 | 26.9 | 21.6 | 20.5 | 10.6 | 2.74 (1.29) |
| My family is able to enjoy activities in our community. | 9.2 | 24.0 | 27.6 | 29.7 | 9.5 | 3.06 (1.13) |
| **Physical/material well-being** | | | | | | **3.88 (0.86)** |
| My family members have transportation to get to the places they need to be. | 3.5 | 6.0 | 8.5 | 37.5 | 44.5 | 4.13 (1.04) |
| My family gets medical care when needed. | 1.8 | 8.8 | 12.4 | 35.3 | 41.7 | 4.06 (1.03) |
| My family has a way to take care of our expenses. | 8.8 | 21.9 | 18.0 | 30.0 | 21.2 | 3.33 (1.23) |
| My family gets dental care when needed. | 7.4 | 12.7 | 8.8 | 31.4 | 39.6 | 3.83 (1.28) |
| My family feels safe at home, work, school, and in our neighborhood. | 2.1 | 7.1 | 10.6 | 44.2 | 36.0 | 4.05 (0.97) |
| **Disability-related supports** | | | | | | **3.08 (0.89)** |
| My family member with a disability has support to accomplish goals at school or workplace. | 11.0 | 17.7 | 22.3 | 37.8 | 11.3 | 3.21 (1.19) |
| My family member with a disability has support to accomplish goals in the community. | 11.3 | 22.6 | 30.0 | 30.7 | 5.3 | 2.96 (1.10) |
| My family member with a disability has support to accomplish goals at home. | 4.6 | 14.8 | 25.4 | 42.4 | 12.7 | 3.44 (1.04) |
| My family member with a disability has support to make friends. | 17.7 | 26.5 | 21.9 | 26.1 | 7.8 | 2.80 (1.23) |

| | | | | | |
|---|---|---|---|---|---|
| My family has good relationships with the service providers who provide services and support to our family member with a disability. | 9.5 | 20.5 | 40.3 | 22.3 | 7.4 | 2.98 (1.05) |
| **Parenting children/adults** | | | | | | **3.78 (0.76)** |
| My family members help them learn to be independent/ increase independence. | 1.4 | 7.8 | 19.5 | 50.6 | 20.9 | 3.79 (0.90) |
| My family helps them with schoolwork/activities. | 1.4 | 6.7 | 19.4 | 48.0 | 24.4 | 3.85 (0.91) |
| My family teaches/supports them in getting along with        others. | 1.1 | 8.5 | 17.4 | 50.5 | 22.6 | 3.83 (0.90) |
| My family teaches/helps them to make good decisions. | 1.1 | 6.0 | 19.8 | 49.2 | 24.4 | 3.87 (0.88) |
| My family knows other people in their lives (e.g., friends, teachers, caregivers). | 2.8 | 7.8 | 14.9 | 47.0 | 27.5 | 3.85 (0.99) |
| My family has time to take care of the individual needs of every child/their needs. | 3.9 | 14.1 | 24.1 | 43.1 | 14.5 | 3.45 (1.03) |

**Q2:  For families of minor and adult children with disabilities, how does FQOL compare between those who participate in parent-peer mentoring programs and those who do not?**

Descriptive statistics and independent-sample t-tests were used to determine whether a difference existed between sample means of respondents who participated in parent-peer mentoring programs and those who did not.  Most families had never participated in such programs (71%), though 55% of those said they would like to.  For those who took part in parent-peer mentoring programs at least a few times, FQOL ratings were slightly higher ($M = 3.54$, $SD = 0.66$) than those who had gone one or twice, or not at all ($M = 3.17$; $SD = 0.13$).  Details are provided in Table 6.

Table 6

*Parent-to-Parent Support and FQOL*

| Participation Frequency | *n* (*N* = 283) | % (*N* = 283) | FQOL M (SD) |
| --- | --- | --- | --- |
| Lots of times! | 25 | 8.8 | 3.5228 (.65527) |
| A few times | 33 | 11.7 | 3.5467 (.66389) |
| Once or twice | 25 | 8.8 | 3.1729 (.12994) |
| No, but I'd like to | 111 | 39.2 | 3.3507 (.67788) |
| No, not interested | 89 | 31.4 | 3.7127 (.66231) |

Table 7

*Effect of Parent-to-Parent (P2P) Support on FQOL Composite and Domain Scores*

|  | P2P | | | No P2P | | | | | |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
|  | M | SD | n | M | SD | n | t | df | p |
| Composite | 3.5364 | .65450 | 58 | 3.4741 | .69534 | 225 | -.615 | 281 | .539 |
| FI | 3.9598 | .74556 |  | 3.7323 | .86533 |  | -1.834 | 281 | .068 |
| P | 3.8980 | .72565 |  | 3.7459 | .76717 |  | -1.361 | 281 | .175 |
| DRS | 3.0379 | .90104 |  | 3.0862 | .89335 |  | .366 | 281 | .714 |
| EWB | 2.8931 | .90551 |  | 2.9280 | .97923 |  | .246 | 281 | .806 |
| PMWB | 3.8931 | .83621 |  | 3.8782 | .86392 |  | -.118 | 281 | .906 |

When comparing the means for respondents who participated in a parent-peer mentoring program (few times, a lot of times) to those who had not (1-2 times, no but would like to, and not interested), t-tests indicated no significant differences between the composite score or any of the domain scores. Composite mean scores were higher for participants who had attended a parent mentoring group a few times to a lot of times (Mean difference -.615; p-value .539). Domains in which the mean scores were higher included PMWB (mean difference -.118; p-value .906), P

(mean difference -1.361; p-value .175) and FI (mean difference -1.1834; p-value .068).

**Other supports**. Other supports identified as most helpful by families were connecting with other parents individually (44%), counseling (41%), informational training/workshops (39%), other support groups (34%), family activities designed for families living with disability (33%), respite services (29%), and activities for individual with disabilities without parents/caregivers (28%).

## Q3:  What other relationships exist between family demographics and FQOL?

Descriptive statistics were utilized to answer the third research question for this study. This question examined the relationship between various demographic factors and FQOL by comparing group means.  Item means for demographic information are displayed in Table 7.

**Parent age.**  Parents aged 21-30 had the highest FQOL ratings ($M = 3.87$, $SD = 0.64$) followed by those over 60 ($M = 3.60$, $SD = 0.63$).  All age groups in between ranged between a mean of 3.41 ($SD = 0.69$) and 3.47 ($SD = 0.65$, 0.73).

**Parent gender.**  Mothers reported a higher mean level of satisfaction ($M = 3.50$, $SD = 0.68$) than fathers ($M = 3.38$, $SD = 0.80$), and both were higher than one individual who reported gender as "other" ($M = 2.85$).  The FQOL satisfaction rated by the individual identifying gender as "other" was the lowest reported of all demographic items, but was based on a single response, so may not be representative of this demographic.

**Ethnicity.**  Participants reporting ethnicity other than "Caucasian" made up a very small portion of the study sample, with only 1-3 members per group in 4 of 6 categories.  In order to make a more meaningful comparison of satisfaction by ethnicity, respondents were grouped as Caucasian and non-Caucasian, and in this case, Caucasian families reported higher FQOL ($M = 3.51$) than non-Caucasian families ($M = 3.32$).

**Age of child with disability.**  Highest FQOL ratings relative to child age were found in families of adult children aged 55+ ($M = 3.61$, $SD = 0.74$) and elementary aged 6-10 year olds ($M = 3.60$, $SD = 0.68$).  As children moved into their teens and transition age, mean FQOL ratings dropped from 3.53 ($SD = 0.62$) for 11-14 year olds, to an all-time low of 3.20 ($SD = 0.81$) for 18-21 year olds, before moving back up again over the span of adulthood.  In addition, the mean rating for this item was the lowest of all demographic items in this study, with the exception of a rating based on a single response, identifying the respondent's gender as "other".

**Time since diagnosis.**  Families who received a diagnosis for their child within the past year had lower FQOL ($M = 3.35$, $SD = 0.42$) than those whose children were diagnosed for longer periods of time, though ratings did not increase systematically over time.  The highest FQOL ratings were found in families with a diagnosis for 1-4 years ($M = 3.55$, $SD = 0.64$), after which satisfaction rose, fell, and rose again over time.

**Gender of child with disability.**  FQOL satisfaction was somewhat higher for parents of female children with disabilities ($M = 3.52$, $SD = 0.68$) than for male children ($M = 3.47$, $SD = 0.70$), and lowest for families indicating child gender as "other" ($M = 3.38$, $SD = 0.17$)

**Child disability type.**  In terms of child disability type, highest FQOL was found in families of children with vision and/or hearing disabilities ($M = 3.66$, $SD = 0.67$) and the lowest was in families of children with emotional/behavioral disabilities ($M = 3.31$, $SD = 0.69$).

**Disability support needs.**  Participants were asked to rate support needs for their minor and adult children with disabilities, at home, school, work, and community environments.  Level of support need was assigned a numerical value of 1-5 and categorized in the following manner: *1 = full support, 2 = quite a bit, 3 = some, 4 = a little, 5 = none, 6 = not applicable.*  A mean was taken of ratings provided for this item, removing responses of "not applicable" from

calculations, and used to identify a score for overall support needs by respondent.  Each score was then rounded to the nearest whole number, corresponding with categories for level of support, so that FQOL could be compared directly by level.  A negative correlation was found between level of support needs and FQOL, so that respondents with the highest support needs indicated the lowest FQOL ($M = 3.29$, $SD = 0.74$) and those with the lowest support needs indicated the highest FQOL ($M = 4.03$, $SD = 0.60$).

**Median income by zip code.**  Median income by zip code reflects local economics, which may influence FQOL in a number of ways (e.g., employment opportunities, community resources, etc.), and in this study was characterized by the greatest variability between item means, with a difference of 0.76 between the highest and lowest rated items.  The highest FQOL ratings in this area were from respondents living in places with a median income of less than $32,000 per year ($M = 4.12$, $SD = 0.40$).  Furthermore, the FQOL mean of this group was higher than that of any other demographic item mean in this study.  The lowest FQOL ratings in this area were for median income levels of $67,001-$99,000 ($M = 3.36$, $SD = 0.67$).

**Community type.**  Community type refers to the size of community in terms of population per square mile.  The highest FQOL ratings in this area were associated with suburban communities ($M = 3.51$; $SD = 0.69$), followed closely by desert communities ($M = 3.50$; $SD = 0.76$).  The lowest satisfaction in this area was in cities/towns ($M = 3.43$; $SD = 0.89$).  Overall, however, community type had only a .08 difference between the highest and lowest ratings, which was the least amount of difference found in item means of all demographic categories.

**Trauma in last year.**  When asked if they had experienced a divorce, death, or other traumatic event in their immediate family over the past year, 212 respondents (75%) indicated

they had.  Of those who had experienced recent trauma, mean FQOL was higher ($M = 3.56$; $SD = 0.67$) than for those who had not ($M = 3.26$; $SD = 0.69$), both overall and across all domains, when considered separately.

Table 8

*Demographic Factors and FQOL*

| Demographic Variables | $n$ ($N = 283$)[a] | % ($N = 283$)[a] | *FQOL M (SD)* |
|---|---|---|---|
| Age of parent/caregiver ($N = 282$) | | | |
|    21-30 | 23 | 8 | 3.87 (0.64) |
|    31-40 | 82 | 29 | 3.47 (0.65) |
|    41-50 | 102 | 36 | 3.41 (0.69) |
|    51-60 | 48 | 17 | 3.47 (0.73) |
|    61+ | 28 | 10 | 3.60 (0.63) |
| Gender of parent/caregiver | | | |
|    Female | 262 | 93 | 3.50 (0.68) |
|    Male | 20 | 7 | 3.38 (0.80) |
|    Other | 1 | <1 | 2.85 ( - ) |
| Ethnicity | | | |
|    Caucasian | 247 | 87 | 3.51 (0.65) |
|    Non-Caucasian - combined | 36 | 13 | 3.32 (0.92) |
| Age of child | | | |
|    0-5 | 33 | 12 | 3.46 (0.52) |
|    6-10 | 67 | 24 | 3.60 (0.68) |
|    11-14 | 50 | 18 | 3.53 (0.62) |
|    15-18 | 36 | 13 | 3.40 (0.74) |
|    19-21 | 27 | 10 | 3.20 (0.81) |
|    22-35 | 41 | 14 | 3.46 (0.71) |
|    35-55 | 14 | 5 | 3.55 (0.75) |

| | | | |
|---|---|---|---|
| 55+ | 15 | 6 | 3.61 (0.74) |
| Gender of child | | | |
| Female | 98 | 35 | 3.52 (0.68) |
| Male | 182 | 64 | 3.47 (0.70) |
| Other | 3 | 1 | 3.38 (0.17) |
| Years since diagnosis | | | |
| Less than 1 year | 13 | 5 | 3.35 (0.42) |
| 1-4 years | 73 | 26 | 3.55 (0.64) |
| 5-10 years | 82 | 29 | 3.45 (0.70) |
| 11-15 years | 37 | 13 | 3.52 (0.71) |
| 15+ years | 78 | 28 | 3.47 (0.74) |
| Disability type | | | |
| Autism | 126 | 45 | 3.33 (0.65) |
| Emotional/behavioral disability | 91 | 32 | 3.31 (0.69) |
| Intellectual/developmental disability | 120 | 42 | 3.47 (0.72) |
| Learning disability | 25 | 9 | 3.43 (0.68) |
| Physical or health impairment | 102 | 36 | 3.62 (0.61) |
| Speech/language disability | 93 | 33 | 3.42 (0.66) |
| Vision and/or hearing disability | 48 | 17 | 3.66 (0.67) |
| Disability support needs | | | |
| Full support | 76 | 27 | 3.29 (0.74) |
| Quite a bit | 94 | 33 | 3.42 (0.66) |
| Some | 83 | 29 | 3.59 (0.63) |
| A little | 24 | 9 | 3.88 (0.59) |
| None | 6 | 2 | 4.03 (0.60) |
| Median income by zip code ($N = 274$) | | | |
| Less than $32,000 | 6 | 2 | 4.12 (0.40) |
| $32,001-$47,000 | 59 | 22 | 3.52 (0.66) |
| $47,001-$67,000 | 129 | 47 | 3.86 (0.85) |

| | | | |
|---|---|---|---|
| $67,001-$99,000 | 72 | 26 | 3.36 (0.67) |
| $99,001-$200,000 | 8 | 3 | 3.84 (0.60) |
| Community Type (*N* = 274) | | | |
| Desert (100 or less) | 26 | 9 | 3.50 (0.76) |
| Rural (101-1,000) | 127 | 46 | 3.48 (0.65) |
| Suburban (1,001-5,000) | 101 | 37 | 3.51 (0.69) |
| City/town (5,001-25,000) | 20 | 7 | 3.43 (0.89) |
| Trauma in past year | | | |
| Yes | 212 | 75 | 3.56 (0.67) |
| No | 71 | 25 | 3.26 (0.69) |

[a]*N* = 283 unless otherwise noted in variable heading.

**Chapter 5**

**Discussion**

The purpose of this survey was to examine family quality of life in families of minor and adult children with disabilities living in the home.  This descriptive study attempted to expand on current literature by extending results from the Beach Center *FQOLS* to include families of adults with disabilities, and by exploring the differences in FQOL between families who have participated in parent-to-parent peer mentoring programs and those who have not.  The majority of participants indicated feeling neutral to satisfied with their overall family quality of life.  For families who participated in parent-peer mentoring programs, there was no clear distinction in FQOL between those who participated and those who did not, though the difference approached significance in the Family Interaction domain.  The following discussion will detail connections with the existing literature and findings from this study.

**Overall FQOL**

The results from this study are similar to those found in the existing FQOL literature in a number of ways.  First, as noted during development of the *FQOLS-2006*, families tended to express a degree of satisfaction with their overall quality of life (Brown et al., 2003).  Compared to families of typically developing children, the literature describes these families as experiencing more stress (Liesen, 2014; Lundy, 2012), with increased sibling adjustment problems (Fisman et al., 2000), less marital satisfaction and more caregiver burden (Gardiner & Iarocci, 2012), along with increased emotional difficulties with feelings of guilt and worry (Al-Kreenawi et al., 2011).  As a result, it may be surprising that overall FQOL tends to be rated between neutral and satisfactory, rather than characterized by dissatisfaction.  One explanation of this phenomenon is that families try to maintain a positive focus despite adversity (Brown et al.,

2003).  Other research has emphasized strength and resilience in families, where a child's

disability is considered a positive factor, contributing to growth and transformation to the benefit

of the family (Bayat, 2007; Dykens, 2005; King et al., 2005).

Individual domain ratings in this study also maintained parallels with previous research.

For example, Family Interaction continued to receive high ratings compared to other areas,

indicating general satisfaction with the family's ability to enjoy time together, solve problems,

and demonstrate support and caring.  Likewise, the domains of Emotional Well-Being and

Disability-Related Support mirrored previous findings, demonstrating low satisfaction with stress

relief, support from friends, time to address individual needs and interests, enjoyment of

community activities, good relationships with disability service providers, and support for family

members with disabilities to make friends and reach goals at school, work, home, and in the

community.  These findings are consistent with other studies using the *FQOLS-2006* (Bertelli et

al., 2011; Brown et al., 2003; Brown et al., 2006; Neikrug et al., 2011; Petrowski et al., 2008;

Schertz et al., 2016) and the Beach Center *FQOLS* (Boehm et al., 2015; Davis & Gavidia-Payne,

2009; Eskow et al., 2011).

**Demographic Factors**

Demographic factors in this study applied to parents and guardians as respondents, as

well as their children.  For parents, the highest FQOL ratings were associated with those who

were Caucasian, female, between the ages of 21-30, and living in suburban areas and/or

communities with a median annual income of less than $32,000.  Lowest ratings were found for

those who were non-Caucasian, male, aged 41-50, and living in cities/towns and/or areas with a

median income of $67,000-$99,000.  No other studies were found comparing FQOL across

parent demographic areas, or exploring possible influences of local median income.

Family finances have been identified as a significant predictor of FQOL, with satisfaction increasing in correspondence with income level (Brown et al., 2006; Davis & Gavidia-Payne, 2009; Schertz et al., 2016; Wang, Turnbull, et al., 2004).  This effect is generally attributed to improved access to resources and services available with higher socio-economic standing (Brown et al., 2006; Cagran et al, 2011; Davis & Gavidia-Payne, 2009; Hu et al 2012; Neikrug et al. 2011; Petrowski et al., 2009; Wang, Turnbull et al., 2004).  It may also be expected that communities with a high median income would have more services and resources available, in turn creating a positive impact on family quality of life.  However, this assumption was not supported by the results of this study.  Perhaps the more inclusive group membership offered by small close-knit communities (Aznar & Castenon, 2005; Hu et al., 2012), which also tend to have less income per capita, better enhances FQOL than the formal supports which are more common to communities with stronger economics.

With respect to child characteristics, families receiving a diagnosis for their child within the past year had lower FQOL than those whose children were diagnosed for longer periods of time, which reflected earlier findings in the literature (Gardiner & Iarocci, 2012; Levison, 2015). The highest FQOL ratings were found in families with a diagnosis for 1-4 years, after which satisfaction rose, fell, and rose again over time.  FQOL was slightly higher for parents of girls than boys.  In extending the use of the Beach Center *FQOLS* to use with families of adults with disabilities, it was interesting to note little difference in FQOL between child and adult age groups overall.  However, families of transition age children rated their satisfaction much lower than those for any other age group, and demonstrated the lowest group mean of any other survey item.  These results may not be surprising, considering challenges associated with times of transition in the literature (Gardiner & Iarocci, 2012; Minnes et al., 2007).  Highest age-related

FQOL ratings corresponded to families with children aged 6-10 years, those with hearing and/or vision impairments, and those with the least support needs.  Lowest satisfaction was indicated for families of children aged 19-21, with emotional/behavioral disabilities, and needing full support across environments.

The negative correlation between FQOL and level of disability support needs observed in this study is in alignment with previous results in this area (Boehm et al., 2015; Gardiner & Iarocci, 2015).  Furthermore, emotional/behavioral disabilities were associated with the lowest FQOL of all disability types, reflecting similar findings related to challenging behavior (e.g., Boehm et al., 2015; Brown et al., 2006; Davis & Gavidia-Payne, 2009; Schertz et al., 2016).  For families of children with autism, FQOL ratings were very close to those with emotional/behavioral disabilities, also supporting previous findings indicating lower well-being in families of children with autism, with increased stress and depression (Dabrowska & Pisula, 2010; Ingersoll et al., 2011; Totsika et al., 2011), and unmet needs in health care, family support, and service referral (Kogan et al., 2008).

**Parent-to-Parent Support**

Parent peer mentoring programs have been credited with aiding parents in managing day-to-day stress and challenges (Hastings & Beck, 2004), and providing opportunities for sharing feelings and information, problem solving, and meeting individual parent needs separate from their child (Winch & Christoph, 1998).  It has provided a framework to decrease isolation, increase moral support, and provide an opportunity to develop relationships characterized as more equal and less discriminatory (Ainbinder et al., 1998; Hammarberg et al., 2014; Kane et al., 2007; Kerr & McIntosh, 2000; McCabe, 2008; McConnell et al., 2012, Winch & Christoph, 1988).  Furthermore, it has helped resolve feelings of confusion, guilt, anxiety, anger, and

depression (Kane et al., 2007; Kerr & McIntosh, 2000; Ainbinder et al., 1998; Singer et al., 1999).  Further benefits include the buffering of stress and improved coping, which in turn, contribute to overall well-being (Hammarberg et al., 2014; Ires et al., 2001; Tadema & Vlaskamp, 2009).

Parent-to-parent peer support offers a number of benefits which are associated with family quality of life in the literature.  While no significant differences were detected in FQOL based on participation in these groups, mean ratings were higher for respondents who took part at least a few times compared to those who attended once or twice, or not at all.  Furthermore, when examining the individual domains, respondents who participated in the parent mentoring program (at least a few times or more) had greater mean scores in the Family Interaction and Parenting domains. While these same respondents scored lower for the other domains.  It is also noteworthy that, while 71% of families surveyed had not participated in parent-to-parent mentoring services, over half (55%) of those families expressed interest in such a program.

There are a number of reasons that the parent mentoring model may not have demonstrated significant findings in this study, when the related literature indicates a history of positive outcomes (Ainbinder et al., 1998; Hammarberg et al., 2014; Kane et al., 2007; Kerr & McIntosh, 2000; McCabe, 2008; McConnell et al., 2012, Winch & Christoph, 1988).  First, the sample size was small, with 58 parents, out of a total of 283, indicating they had participated a few times or more.  Furthermore, markers on the item describing how often a responder participated in a parent mentoring program (i.e., dosage markers) were vague. The markers included "would not like to", "not at all", "1-2 times", "a few times", "a lot of times". These markers may have led to wide variability in the interpretation of the phrases "a few times" and "lots" of times".  It may be possible that parents did not have enough experience attending the

program to reap the benefits, and the survey was not able to distinguish this as a result of vague phrasing.  It may be that parent mentoring support simply does not address what the FQOLS is measuring.

A distinct overlap is clear between many of the cited benefits of parent peer mentoring, and domain indicators for FQOL.  Many of the examples above would categorize easily into the Family Interaction domain, where measures include enjoying each other's company, talking openly, solving problems together, supporting each other to accomplish goals, showing care for each other, and handling life's ups and downs.  This overlap may explain the higher FQOL ratings relative to this domain.  In the Parenting domain, items refer to gaining assistance from family members in teaching the children, taking care of their needs, and knowing the other people in their lives.  These items are not as directly related to parent mentoring programs outcomes as those in the Family Interaction domain, but gaining new information and a sense of community may increase self-efficacy in parents, which may in turn influence FQOL.  Under Emotional Well-Being, the items "having support to relieve stress" and "having friends who provide support" would encompass interpersonal parent-to-parent outcomes and those associated with stress relief.  Items in Physical and Material Well-Being and Disability-Related Support are not directly addressed, though parent-peer support might provide information helpful to meeting needs in these areas.

The overlapping of these items would indicate the strongest influence by parent mentoring support programs on the domains of Family Interaction, Emotional Well-Being, and possibly Parenting.  The results of this study support this analysis with respect to Family Interaction and Parenting, but not Emotional Well-Being.  This discrepancy may appear as a result of small sample size or inadequate dosage, or perhaps as a result of less correspondence

between domain items and demonstrated parent-to-parent support outcomes.  Furthermore, since Family Interactions and Parenting tend to be more highly rated than other domains, parent-to-parent mentoring programs may produce more significant results if targeted more intentionally to domain items which are more likely to be rated low.

**Study Limitations**

The target population for this study was a national sample of parents or guardians who were the primary caregivers of individuals with disabilities living at home.  Results should be reviewed and generalized with caution, as participants were comprised of volunteers who participated via email and social media, and did not constitute a random sample.  The sample size was small, and did not fully represent the diversity of a true national sample, despite efforts to encourage broad participation.  Furthermore, the use of a survey design allowed for response bias, posing a threat to validity and reliability, and the use of individual reports to describe the family unit did not allow for the perspective of all family members to be included.  Additionally, the use of undefined dosage markers to describe level of participation in parent-to-parent activities allowed for broad variation in how respondents may have categorized their experiences.  Finally, survey adaptations, while expanding the use of the *FQOLS* to families of adult children, may have affected the reliability and validity of the instrument.  Results may not be easily compared with those in other studies, specifically in the domains of Parenting, Emotional Well-Being, and Disability-Related Support, since items in those areas were altered.

**Recommendations for Future Research**

Additional study should be dedicated to increasing FQOL in families of children and adults with disabilities.  Research should continue to explore models of parent support responsible for increasing the FQOL.  The field could potentially align the development of

resources with the domains of such measures as the *FQOLS* and *FQOLS-2006*.  In addition, measures of FQOL should also include other family members as respondents. While parents will continue to age, and the burden of planning the future of their child with disabilities will weigh heavily on them, siblings and other family members will likely take on primary caregiving roles as the children age.  In addition, it will be important to identify the role that culture has on FQOL measures, in order to better align resources for diverse family needs.  Finally, this line of research should begin to direct policy and funding to better identify those variables that influence FQOL and thus outcomes for individuals with disabilities.

**Conclusion**

Providing supports for families of individuals with disabilities is important for the well-being of the family as well as increasing the likelihood of better outcomes for the individual with a disability.  This study expanded the Beach Center *FQOLS* items to include families of adults with disabilities.  The survey also aimed to examine the influence of demographic factors and participation in parent mentoring programs on FQOL.  Although there were no significant findings, the results of this study indicated a clear interest in parent-to-parent support by families of children with disabilities, and somewhat higher levels of FQOL for those who participated in such a model.  This research may lead the way to future study of FQOL as an informer of program development efforts, family resource needs, directions for future funding, and the development of policy for individuals with disabilities and their families.

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# Appendix

This survey asks for general information about your family, how you rate different parts of your family life on a scale of 1-5 (e.g. My family has the support we need to relieve stress.), and types of disability support you may or may not use.

We will use what we learn to inform policy makers and disability-related service providers, in hopes of providing more meaningful support for families like yours.

Participation in this study may make you more aware of services available, but because it asks about topics that are challenging for some, you may also feel emotional discomfort when thinking about questions you would score with low ratings.  If you experience undue stress, you may choose to seek support from local community resources.

All personal information provided for this study is confidential and will not be shared with other agencies or researchers.  Participation is purely voluntary.  You may refuse to participate at any point, and exit the survey without penalty. If you would like more information about this study, please contact Holly Patton at hollyk5@uw.edu.

By clicking the "I AGREE" button below, I confirm the following:

- This study has been explained to me and I volunteer to take part in this research.
- I am the parent/guardian of a child or adult with disabilities living in my home.
- I am age 21 or older.
- No one else in my household has participated in this survey.
- If I have questions about this research, or if I have been harmed by participating in this study, I may contact the researcher listed above.  If I have questions about my rights as a research subject, I may call the Human Subjects Division at (206) 543-0098.

|  | *Logic destinations* |
|---|---|
| ◯ I AGREE. | ➡ Don't skip (default) |
| ◯ No Thanks. | ➡ Thank you for your time! ... |
| *No response* | ➡ Thank you for your time! ... |

Thank you for agreeing to complete this survey!  First, tell us a little bit about yourself.

How old are you?

- ◯ 20 or younger
- ◯ 21-30
- ◯ 31-40
- ◯ 41-50

○ 51-60
○ 61 or older

What is your gender?

○ Female
○ Male
○ Other

What is your ethnicity?

○ American Indian/Alaskan Native
○ Asian
○ Black/African American
○ Hispanic/Latino
○ Native Hawaiian/Other Pacific Islander
○ White
○ Two or more races

What is your zip code?

In the past 12 months have you experienced a divorce, death, or other traumatic event in your immediate family?

○ No
○ Yes

The next six questions concern the person in your home with disabilities.  If you have more than one person with disabilities living in your home, please think about the one who has the greatest impact on family life when answering these questions.

What is your relationship to this person?

○ Parent
○ Grandparent
○ Sibling
○ Other relative
○ Non-related guardian

○ Other:

How old is this person?

○ Birth to 5 years
○ 6-10
○ 11-14
○ 15-18
○ 19-21
○ 22-35
○ 36-55
○ 56 or more years

What gender is this person?

○ Female
○ Male
○ Other

When did you learn this person had a disability?

○ Less than one year ago
○ 1-4 years ago
○ 5-10 years ago
○ 11-15 years ago
○ Over 15 years ago

Which category(s) below best describes this person's disability? Please check all that apply.

☐ Autism
☐ Emotional/Behavioral Disability
☐ Intellectual/Developmental Disability
☐ Learning Disability
☐ Physical or Health Impairment
☐ Speech/Language Disability
☐ Vision and/or Hearing Disability
☐ Other:

How much support does this person need to be successful in the following places:

*Rows*

At school?

At work?

At home?

In the community?

○ Full support

○ Quite a bit

○ Some

○ A little

○ None

○ N/A

Below are general questions about your family.  For this survey, please consider:

**Family** = people who support and care for each other on a regular basis, even if they are not related by blood or marriage.

**Do not include** relatives who are only involved with your family every once in a while.

The items below are things that hundreds of families have said are important for a good family quality of life.

We want to know **how satisfied** you have been with these things in your family over the past 12 months.

## My family . . .

*Rows*

enjoys spending time together

has the support we need to relieve stress

has friends or others who provide support

has transportation to get where we need to be

talks openly with each other

has some time to pursue our own interests

is able to enjoy activities in our community

solves problems together

supports each other to accomplish goals

shows that they love and care for each other

gets dental care when needed

feels safe at home, work, school, and in our neighborhood

has outside help available to take care of all family members' unique needs

is able to handle life's ups and downs

gets medical care when needed

has a way to take care of our expenses

- ○      Very Dissatisfied
- ○      Dissatisfied
- ○      Neutral
- ○      Satisfied
- ○      Very Satisfied

**How satisfied** have you been with the following over the **past 12 months**, for your family member with a disability?

## My family member with a disability has support to . . .

*Rows*

accomplish goals in school or work

accomplish goals in the community

accomplish goals at home

make friends

My family has good relationships with disability related service providers

- ○      Very Dissatisfied
- ○      Dissatisfied
- ○      Neutral
- ○      Satisfied
- ○      Very Satisfied

Do you have one or more minor children living in your home?

| | *Logic destinations* |
|---|---|
| ○ Yes | ➡ Don't skip (default) |
| ○ No | ➡ Question 18: How satisfied are you with ... |
| *No response* | ➡ Don't skip (default) |

How satisfied are you with the following, for **ALL minor children** living in your home?

*Rows*

My family helps them to learn independence

My family helps them with schoolwork or activities

My family teaches them how to get along with others

My family helps teach them to make good decisions

Family adults know other people in the children's lives (friends, teachers, etc.)

Family adults have time to take care of each child's needs

○      Very Dissatisfied

○      Dissatisfied

○      Neutral

○      Satisfied

○      Very Satisfied


How satisfied are you with the following, for **<u>adult family members with disabilities</u>** living in your home?

# My family . . .

*Rows*

helps them to increase independence

helps them with activities

supports them in getting along with others

helps teach them to make good decisions

knows people in their lives (friends, caregivers, etc.)

has time to take care of their needs

○      Very Dissatisfied

○      Dissatisfied

○      Neutral

○      Satisfied

○      Very Satisfied


We're almost done!  Now just a couple more questions about disability-related support you may have received.

Parent mentoring programs connect you with trained parents who have children (minor and adult) with similar needs to yours, to answer questions

and provide support. One such program is Parent to Parent (P2P).

Have you ever participated in a parent mentoring program?

| | |
|---|---|
| ◯Lots of times! | ➡ Don't skip (default) |
| ◯A few times. | ➡ Don't skip (default) |
| ◯Once or twice. | ➡ Don't skip (default) |
| ◯No, but I would like to. | ➡ Question 22: Please check any other disa... |
| ◯No, not interested. | ➡ Question 22: Please check any other disa... |
| *No response* | ➡ Don't skip (default) |

What program or programs did you participate in?

How satisfied were you with . . .

*Rows*

Your parent mentor connection?
Information you received?
Other activities or services?

◯ Very Dissatisfied
◯ Dissatisfied
◯ Neutral
◯ Satisfied
◯ Very Satisfied
◯ N/A

Please check any other disability-related activities or services that you have used and found helpful.

☐Respite services
☐Counseling
☐Support groups
☐Connections with other parents/guardians in person or by phone
☐Connections with other parents/guardians online
☐Informational training/workshops
☐Family activities (designed for families living with disabilities)

☐Activities for individuals with disabilities (without parents/caregivers)

☐None

☐Other:

Comments?

Thank you for your time!

If you know of anyone else who would be interested in participating, please feel free to **forward the survey link**.

The more families we hear from the better!