

Predictors of Family Quality of Life Among Parents of
Children and Adults with Intellectual Disability

By

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To my beloved wife, Lisa, and my five children, Marly, Seth, Max, Samuel, and Gabriel.

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CHAPTER 1

INTRODUCTION

Improving the quality of life for individuals with intellectual disability (ID) and their families has been a growing area of research for over three decades. The individual quality of life (QOL) construct emerged within the ID field in the late 1980's followed by the family quality of life (FQOL) construct in the 2000's (Schippers, Zuna, & Brown, 2015). Leading disability journals have devoted special issues to introducing FQOL within a QOL framework (Brown, Schalock, & Brown, 2009) and focusing on specific conceptual issues, measurement tools, and empirical findings (Kober & Wang, 2011, 2012). Books also have been dedicated to synthesizing and disseminating what is known about FQOL among individuals with ID and their families (Brown & Faragher, 2014; Kober, 2010; Turnbull, Brown, & Turnbull, 2004). Collectively, this growing body of literature offers guidance for those interested in supporting and improving the quality of life for families impacted by ID. As Brown, Anand, Fund, Isaacs, and Baum (2003) note, one reason for this international interest in FQOL is that "increasingly, governments and other funding sources in developed countries are turning to families to provide the principal care to both children and adults of all ages with disabilities" (p. 208).

An early definition of the FQOL construct was, "Conditions where the family's needs are met, and family members enjoy their life together as a family and have the chance to do things which are important to them" (Park et al., 2003, p. 368). Mirroring the general conception of QOL as "the goodness of life," FQOL has also been defined as "the goodness of family life" (Brown & Brown, 2004). FQOL focuses on family life and well-being beyond that of individual

family members. Zuna, Summers, Turnbull, Hu, and Xu (2010) proposed a more precise definition of FQOL as “a dynamic sense of well-being of the family, collectively and subjectively defined and informed by its members, in which individual and family-level needs interact” (p. 262).

A number of descriptive studies have provided insight into the FQOL of families with a member with ID. In their study of 425 parents of youth and young adults (ages 13-21) with ID and/or autism spectrum disorder (ASD) in Tennessee, Boehm, Carter, and Taylor (2015) reported mean satisfaction ratings of 3.99 on a 5-point scale using the Beach Center Family Quality of Life Scale. Their sample, however, also included parents of individuals with either ASD only or both ID and ASD and comparative analyses between subgroups were not reported. Among studies including only caregivers of individuals with ID, Svraka, Loga and Brown (2011) reported a mean of 3.68 (5-point scale using the Family Quality of Life Survey 2006) among 35 mothers of adult children (ages 19-32). Caples and Sweeny (2011) included 49 parents ranging in age from 33-81 of both children and adults with ID in Ireland; 88% reported FQOL as *good* to *excellent* (using the Family Quality of Life Survey 2006). McFelea and Raver (2012) included 54 parents of children (ages 6-21) with severe to profound ID in Virginia either living at home ($n = 25$) or in a residential facility ($n = 29$) and reported similar mean satisfaction ratings of 3.84 and 3.95 respectively (5-point scale using the Beach Center Family Quality of Life Scale).

Although these findings collectively suggest moderate to high FQOL of families with sons or daughters with ID, the current literature has important gaps when describing these families' FQOL. Existing studies have one or more of the following five specific limitations. First, samples are of mixed disability types including ASD and other developmental disabilities. For example, because Boehm and colleagues do not report ID subgroup FQOL ratings,

descriptive findings from that study portray FQOL for parents of young people with ID only, ASD only, and ID plus ASD combined. Second, samples are of narrow age ranges. For example, Svraha and colleagues (2011) only included parents with adult children. Third, samples are of homogeneous disability severity. For example, McFela and Raver (2012) only included individuals with severe or profound ID. Fourth, samples are from a single geographic region. For example, Summers and colleagues reported FQOL ratings limited to parents living in a Midwestern state; Holloway, Domínguez-Pareto, Cohen, and Kuppermann (2014) reported FQOL ratings limited to parents living within the state of California. Fifth, samples within the United States are relatively small in size. For example, among ID-only studies in the United States, none had samples larger than 54 parents. A study is needed therefore that addresses all of these limitations. Specifically, there is need to examine FQOL among a larger and more diverse sample of parents whose son or daughter has ID to ensure descriptive FQOL findings reflect the population of families with members with ID. This diversity should include heterogeneous disability severity and a broad range of ages with parents whose child is very young to those whose children are well into adulthood. Additionally, regional diversity is needed to ensure perceptions of life quality among families living in different areas of the United States are represented. This broader representation from larger and more diverse samples will result in a stronger empirical foundation upon which to craft family-related policies and develop or refine professional family support practices (Reynolds et al., 2015).

It is also important to account for variations in FQOL ratings between families and determine how FQOL may be shaped by various factors. Zuna, Turnbull, and Summers (2009) proposed a unified theory of FQOL to help researchers explore relationships among relevant variables and explain differences in FQOL ratings. This unified theory reflects an ecological

model (Bronfenbrenner, 1986) with four increasingly complex types of factors: (a) individual family members, (b) family unit, (c) performance, and (d) systemic. Individual family member factors include both parent and child demographics (e.g., age, gender) anchored in the individual. Family unit factors include those things that effect the entire family (e.g., family income, household size). Performance factors include all the specific activities done to, for, or with individuals with ID and their families. This includes the services, supports, and practices expected to add value to the physical, emotional, or relational lives of family members. Systemic factors include the systems (e.g., healthcare, education), policies, and programs designed to support families. This unified FQOL theory provides a helpful model for summarizing FQOL research to date and proposing new directions in understanding FQOL and the factors that shape it. In the following sections, I review relevant research on individual child factors, individual parent factors, family unit factors, and performance factors.

Individual Child Factors

Individual factors comprise characteristics of the child and the parent that may contribute to variations in FQOL ratings. Among child factors, challenging behaviors is among the most frequently studied. For example, after controlling for other factors (i.e., family income, family support, professional support), Davis and Gavidia-Payne (2009) found challenging behaviors to be a strong and significant predictor of FQOL among 64 mothers of young children (ages 3-5) with intellectual and developmental disabilities (IDD). Boehm and colleagues (2015) also reported challenging behaviors to be a significant predictor of FQOL among parents of youth and young adults (ages 13-21) with ID and/or ASD. However, these studies are not necessarily representative of parents whose children have ID since other developmental disabilities were

included in the samples. Among studies focused exclusively on parents of children with ID, Foley and colleagues (2014) reported challenging behaviors as a predictor of FQOL among 150 families in Australia with children (ages 16-30) with Down syndrome. However, larger and more representative studies are needed to confirm this association between challenging behaviors and FQOL. Furthermore, statistically controlling for challenging behaviors will enable exploration into other factors that may shape FQOL.

The age of the son or daughter with ID could also help explain FQOL differences. As their children age, parents move from the early years of initial diagnosis with the resulting life adjustments, through the school years with school-based supports, through transition into adult life. Young adults with ID often remain in the family home with unique challenges in finding meaningful work and satisfying relationships (Bogenschutz et al., 2015). These child and parent life stages may differentially influence perceptions of FQOL. Although child age has been found to predict FQOL ratings among parents of children with other IDD (Meral, Cavkaytar, Turnbull, & Wang, 2013), this variable has yet to be examined among parents of children and adults with ID. Child age could be examined by comparing FQOL ratings among parents with school-age versus post-transition age children. Additionally, age could also be used as a continuous variable to examine associations with FQOL across the full life course.

Two additional child factors to consider are disability severity and support needs. Each of these variables reflect the degree to which ID impacts everyday life within a family with potentially both positive and negative contributions. Hu, Wang, and Fei (2012) found greater disability severity predicted lower FQOL satisfaction ratings among 442 parents of sons and daughters with ID (birth to over 18) with three levels of severity represented (i.e., 41% mild, 35% moderate, 9% severe, 15% unknown). Vilaseca and colleagues (2015) reported a similar

predictive relationship among parents and caregivers of individuals (ages 2-70) with mild (20%), moderate (33%), or severe (42%) ID. In contrast, disability severity was not a significant predictor of FQOL among 425 parents of youth and young adults (ages 13-21) with IDD (Boehm et al., 2015). However, conceptualizations of ID have moved beyond using broad categories of severity and toward conceptions of support needs (Thompson et al., 2009). Among studies examining support needs, greater support needs predicted lower FQOL among 70 children (ages 6 months–18 years) with various IDD (Schertz, Karni-Visel, Tamir, Genizi, & Roth, 2016). These support needs were measured with two questions—one about level of physical support needed and one about level of communication support needed—using a 5-point, Likert-type scale. Similarly, greater support needs predicted lower FQOL ratings among 425 parents of youth and young adults (ages 13-21) with IDD (Boehm et al., 2015). These support needs were measured with seven questions about levels of support needed in various settings (e.g., school activities, community and neighborhood activities) using a 5-point Likert-type scale. Therefore, findings on disability severity have been mixed and findings on support needs have relied on different measurement instruments. A study with a large sample of parents of individuals with ID could help elucidate the unique role of these two child factors in shaping FQOL.

Another child factor potential contributing to FQOL relates to the presence of other disabling conditions. Great heterogeneity exists among individuals with ID. This heterogeneity can include cognitive ability, communicative capacity, and behavioral idiosyncrasy. These different disability profiles may differentially impact FQOL. For example, the presence of challenging behaviors can add additional stress on families and consume time and resources for parents to manage. Parents may also face additional challenges in communicating with their child and teaching them basic adaptive and life skills. These challenges may add additional strain

and could depress FQOL. Among the possible disability profiles, ASD has a higher prevalence rate among individuals with ID and is characterized by these communication and behavioral challenges (Wong et al., 2015). In a recent epidemiological study of prevalence rates of ID only, ASD only, or ID plus ASD, Tonnsen and colleagues (2016) reported prevalence rates of over 18% of ASD among individuals with ID as compared to around only 1% in the general population. This increased prevalence of ASD symptomatology among individuals with ID, including the behavioral, social, and communication challenges, may influence a parent's perception of their FQOL. It is therefore important to also account for the presence of ASD as a comorbid diagnosis among individuals with ID.

Individual Parent Factors

Individual parent factors may also contribute to variations in FQOL ratings. Regarding parent role, for example, findings are mixed. Specifically, Wang and colleagues (2006) reported no differences in FQOL ratings between mothers and fathers among 214 parents (107 couples) with children (birth to 5 years) receiving early childhood services. In contrast, Pozo, Sarriá, and Brioso (2014) reported differences (i.e., a lack of correlation) between FQOL ratings among 59 couples with children (ages 4-38) with ASD. How parent role accounts for variability in FQOL ratings among mothers and fathers of individuals with ID only has not been studied. It is important to know whether views about FQOL differ based on parenting role.

Differences in the way parents perceive FQOL may also differ based on education, race/ethnicity, or health status. For example, Vilaseca and colleagues (2015) reported a positive association between FQOL and levels of parent education among parents and caregivers of individuals (ages 2-70) with ID. Higher levels of education may serve as a protective factor by

equipping parents with information and skills to better manage the unique challenges of raising a child with disability, thus enhancing FQOL. Additionally, Cohen, Holloway, Domínguez-Pareto, and Kuppermann (2014) reported higher FQOL among Latina mothers compared with non-Latina mothers of children (ages 2-10) with ID (51%) or ID plus ASD (49%). Perceptions of FQOL may be impacted by the extent to which family life is shaped by racial- or ethnic-specific traditions such as parenting style or degree of autonomy versus dependence upon community for support. Furthermore, a parent's health status could contribute to their FQOL with poorer health having a negative impact on FQOL. The association between health status and perceptions of FQOL has not been examined. A large and representative sample of parents of individuals with ID is needed, therefore, to explore these parent factors and how they relate to FQOL. Furthermore, controlling for these demographic factors will enable exploration into the more complex performance factors and their role in shaping FQOL.

Family Unit Factors

Socioeconomic status (SES) is a family-level factor associated with FQOL. Because disability can add additional family expenses or interfere with a parent's ability to pursue career opportunities, perceptions of FQOL among families of individuals with ID may be differently impacted by SES. However, findings related to this variable are not consistent. Vilaseca and colleagues (2015) reported lower family income predicted lower FQOL among 2,160 parents of individuals (ages 2-70) with ID in Spain. Foley and colleagues (2014) reported the same association among 150 parents of individuals (ages 16-30) with Down syndrome in Australia. In contrast, Cohen et al. (2014) reported income was not a significant predictor of FQOL ratings among 145 mothers of children (ages 2-10) with ID or ID plus ASD. Furthermore, different

indicators of SES have been used in FQOL research, including family income (e.g., Hu et al., 2012) and free and reduced-priced meals (e.g., Boehm et al., 2015). Other SES indicators could also include whether a family receives any disability-related public funding or support. Consistent with a recent call by a diverse cross-section of national disability leaders, the next decade of ID research should focus on socioeconomic status by exploring specific connections between socioeconomic diversity and FQOL (Reynolds et al., 2015). Household size, for example, may have socioeconomic implications and meaningfully relate to FQOL. Specifically, more people living within a house may be a risk factor by adding to the economic burden. Alternatively, a larger household size may be a protective factor by adding more hands to help fulfill family and household management responsibilities.

Performance Factors

Performance factors include activities done to, for, or with individuals with ID and their families. These activities may include the supports families receive that can impact their QOL. Social relationships comprise an important performance factor as they provide a context for receiving emotional or practical support. The influence of social relationships on physical health has been widely reported (e.g., House, Landis, & Umberson, 1988). The mechanisms for this influence, however, are less clear. Social exchange theory attempts to explain this influence by exploring the benefits people derive from, as well as contribute to, their social relationships and interactions with others (Collett, 2010). In a review of positive psychology research on the potential influence of relationships, Caughlin and Huston (2010) assert, “The importance of relationships to personal happiness and well-being is so well established that the most contested debates are not about the *centrality of relationships* but rather about whether certain *types* of

relationships are particularly important” (p. 26, italics added). A parent who has more satisfying and supportive relationships may be more likely to perceive enhanced FQOL. However, knowing how different types of relationships shape FQOL could help inform family support policies and practices by directing resources toward fostering these types of relationships in a parent’s life.

Family relationships, friendships, and relationships parents have with professionals are types of relationships that may shape FQOL in unique ways. For example, better relationships with one’s spouse and children would likely enhance perceptions of FQOL while strained family relationships would likely have the opposite effect. Beyond the family system, a parent’s friends comprise a potentially supportive network of meaningful relationships (Boehm & Carter, 2016) that may also shape perceptions of FQOL—better friend relationships likely enhance FQOL. Additionally, parents impacted by disability often have additional relationships with professionals who offer assistance in a variety of developmental, educational, and health-related needs. Beyond the technical skills and informational access these professionals provide, the quality of relationships or partnerships developed between parent and professional may also contribute to buffering or buffeting perceptions of FQOL. Specifically, a kind and caring professional who is relationally sensitive and supportive may offer something of value to parents beyond the technical services for which the parent pays. Relationships likely shape FQOL and different types of relationships may shape FQOL in unique ways.

Research exploring associations between FQOL and various types of parental relationships have been relatively sparse. Using path analysis among a sample of 118 parents of children and adults (ages 4-38) with ASD, Pozo and colleagues (2014) reported social support had a direct and positive effect on FQOL. The specific persons from whom this social support was derived, however, was not specified. Davis and Gavidia-Payne (2009) reported support from

family and professionals were the strongest predictors of FQOL—after controlling for child, family, and other support characteristics—among 64 mothers of young children (ages 3-5) with IDD. Interestingly, family income was correlated with FQOL in this study but lost predictive value after the influence of support from family and professionals were entered into the regression model. From analyzing qualitative and quantitative results from 25 mothers of individuals (ages 3-28) with ID, Steel, Poppe, Vandeveld, Van Hove, and Claes (2011) highlighted the significance of support specifically from friends and neighbors in shaping FQOL. Additional research into the types of relationships (e.g., family members, friends, or professional service providers)—especially after controlling for individual and family factors—would help elucidate this important performance factor (i.e., social relationships) and its role in shaping FQOL.

Role of Religion/Spirituality

Another possible factor likely associated with FQOL involves religion/spirituality. No universally agreed upon definitions of this multidimensional construct exist (Hall, Meador, & Koenig, 2008). However, it has become popular to conceptualize and define religion and spirituality in distinctive terms. According to this contrastive approach, spirituality is defined in personal and positive terms while religion is considered as one possible outlet for someone's spirituality. Thus, religion is often defined in institutional, as opposed to personal, terms. The saying "I am spiritual but not religious" typifies this contrastive approach to religion/spirituality. An alternative approach to contrasting religion and spirituality is to consider the areas of overlap. In a classic review of religion/spirituality conceptualization and measurement, Hill and Pargament (2003) identify the *sacred* as that which religion and spirituality have in common and

that which distinguishes this factor from other phenomena. Accordingly, the sacred “refers to those special objects or events set apart from the ordinary and thus deserving of veneration...and includes concepts of God, the divine, Ultimate Reality, and the transcendent” (Hill & Pargament, p. 65). Although distinctions can certainly be made between the two, considering religion and spirituality as a single factor that represents the sacred in the life of a person or family (or community) enables empirical examination of this construct and potential contributions to shaping outcomes such as FQOL.

In the years since Poston and Turnbull (2004) first identified the association between religion/spirituality and FQOL among families impacted by disability, other evidence has accumulated. Ajuwon and Brown (2012) reported almost half of the 80 caregivers of school-age children and youth with ID cited their religious practices as positively contributing to their FQOL and more than a third noted their spiritual beliefs as important in their lives. In examining FQOL among 33 families with children (ages 3-13) with Down syndrome, Brown, MacAdam-Crisp, Wang, and Iarocci (2006) reported 73% cited spiritual and cultural activities were somewhat to extremely important in guiding the way they think and act. Boehm and colleagues (2015) examined FQOL among 425 families of young people (ages 13-21) with ID and/or ASD and reported strength of religious faith was one of the strongest predictors; greater faith predicted higher FQOL. Collectively, these findings point to potential associations between FQOL and a parent’s religiousness/spirituality and highlight the importance of considering the sacred dimension of a parent’s life.

Research Questions

Although research over the past two decades has begun to highlight factors associated with FQOL, there is need for additional research with larger and more representative samples that examine both traditional, as well exploratory, variables. Most FQOL studies to date have included smaller sample sizes (i.e., under 100), included parents of children with mixed disability types, and examined relatively few variables. Furthermore, most of this research has considered individual- and family-level factors, such as challenging behaviors and family income, while neglecting other factors such as social relationships and religion/spirituality. Additional research is needed that includes larger samples of parents of children with ID that captures the range of life-cycle experiences and includes an array of factors including performance factors.

In light of the ways social relationships and religion/spirituality may shape family quality of life among parents of individuals with ID, along with individual and family factors, I designed this study to address the following questions.

Research Question 1: How do parents of individuals with ID describe their FQOL?

Research Question 2: Do these FQOL ratings differ based on disability, age, or regional differences?

Research Question 3: What demographic (i.e., child, parent, family), religious/spiritual, and relational factors predict FQOL?

CHAPTER 2

METHODS

Participants

Participants were 529 parents (i.e., biological, step, or adoptive) or primary caregivers (e.g., grandparent, sibling, aunt/uncle) of individuals with intellectual disability (referred to as “parents” in the remainder of this paper). To be included in the study, parents must have been living in Tennessee or Illinois and had a child of any age diagnosed with ID. The full age spectrum allowed for exploration of FQOL and related factors across the lifespan. The two states reflect geographical regions of the country that may differ on factors associated with FQOL. For example, the importance of religion/spirituality tends to be greater in southern states than in Midwestern states (Pew Research Center, 2007). The types and quality of professional services available to families also varies across states (Braddock et al., 2015). Thus, I sampled from these two states to generate a larger and more diverse sample. Of the 826 parents who responded to invitations to participate in the larger study, 297 were excluded from these FQOL analyses for not reporting at least 75% of items on every subscale of the dependent variable (i.e., FQOL) or not reporting any items on at least one of the relational or scaled religious/spiritual variables of interest (i.e., family relationships, friend relationships, professional relationships, overall religiousness/spirituality). Thus, the final sample included 529 parents of individuals with ID.

Parents ranged in age from 27.0 to 91.0 years ($M = 52.7$ years, $SD = 11.3$) with about half living in Illinois ($n = 273$, 51.6%) or Tennessee ($n = 256$, 48.4%). Although the majority (90.7%) identified themselves as female, 87.0% described their relationship to the individual with ID as

that of mother. Among the 523 parents who identified only one race/ethnicity, 459 (86.8%) were White (non-Hispanic) only. Five parents (0.9%) identified as multiple race/ethnicities. Parents variously described their health status as excellent ($n = 77$, 14.6%), very good ($n = 163$, 30.8%), good ($n = 203$, 38.4%), fair ($n = 76$, 14.4%), or poor ($n = 10$, 1.9%). The majority of parents (71.9%) reported receiving some public funding/support; two parents did not provide information for this question. Other parent demographics are displayed in Table 1.

Sons and daughters ranged in age from younger than 1.0 year up through 74.0 years ($M = 21.5$, $SD = 12.2$); 53.9% were age 21 or younger. Over a third (36.1%) was female. Half ($n = 279$, 52.7%) of parents also reported one etiological indicator to further describe their child's disability; 6 (1.1%) indicated two. These etiological indicators included Down syndrome ($n = 169$), cerebral palsy ($n = 80$), Fragile X syndrome ($n = 14$), Fetal alcohol syndrome ($n = 8$), Williams syndrome ($n = 5$), Angelman syndrome ($n = 4$), Cornelia de Lang syndrome ($n = 3$), Klinefelter syndrome ($n = 3$), and one for each of Edward's, Prader-Willi, Rett, Smith-Magenis, and 5p- (*cri du chat*) syndromes. Among parents reporting two indicators, four included cerebral palsy—along with Fetal alcohol syndrome, Cornelia de Lang syndrome, and two with Fragile X syndrome—and the other two reported both Down syndrome along with Klinefelter syndrome. The prevalence of those with an additional diagnosis of ASD was 39.9%. In terms of child age, 139 (50.9%) parents in Illinois and 160 (62.5%) parents in Tennessee had children who were school-age or younger. Additional demographics of sons and daughters are displayed in Table 2.

Recruitment

I used recruitment procedures mirroring those of two recent studies carried out in one of the states (Tennessee) and involving a similar focus population (Blustein, Carter, & McMillan,

2016; Boehm, Carter, & Taylor, 2015). My recruitment goal was 418 parents—at least 209 from each state. This minimum sample size was selected based on an anticipated medium effect size of .15, a strong 95% level of statistical power desired, 17 predictor variables, and an alpha level or probability of Type I error of 0.05 (Cohen, 1988; Soper, 2016).

After receiving approval from the Institutional Review Boards (IRB) of both Vanderbilt University and Wheaton College, I used a two-pronged strategy to send invitations. First, because no statewide list of parents existed, I developed recruitment partners consisting of a variety of disability- and family-focused organizations, groups, and networks who had relationships with families impacted by ID. I conducted an internet search and consulted with disability and family researchers and educators across Illinois and Tennessee to identify organizations and community representatives who have relationships with parents of children with ID across each state. Overall, 147 partnering organizations agreed to distribute recruitment materials (Illinois = 71, Tennessee = 76). Among these, 73 (Illinois = 38, Tennessee = 35) confirmed extending invitations directly to parents; I was unable to confirm invitations were sent by the remaining 74 organizations. Among the partners who confirmed extending parent invitations were 20 disability-specific service providers offering an array of programmatic services (i.e., day programs, early-intervention, residential, employment/vocational, developmental training, parent support, family support, recreation/play, advocacy, camp programs, medical/health), 12 educational service providers (i.e., schools, post-secondary education programs, non-school-based learning programs, and research programs), 12 advocacy and support providers/groups (i.e., Down syndrome associations, autism advocacy groups, cerebral palsy advocacy groups, individual support groups, parent support groups, family support groups, parent to parent/family to family groups), 9 congregation and para-congregation

ministries, 5 Arc chapters, 4 organizations overseeing group homes (including at least 74 individual homes), 3 parent training information centers, 3 individuals, 2 Special Olympics programs, 1 vocational service provider, 1 medical/healthcare professional, and 1 sports/recreation service provider (not Special Olympics).

I provided the following recruitment announcement options, asking partners to adapt each according to their best method for reaching parents: (a) email invitations, (b) print invitations, and (c) short newsletter or website blurbs with links to full invitations. I tracked recruitment efforts by keeping a log of every potential partner contacted, whether they agreed to help by sending out recruitment materials, and which recruitment methods they used. I followed up with each potential partner up to three times to confirm agreed upon recruitment assistance was completed.

Second, I sent 1,507 email invitations directly to parents of children with ID living in Tennessee who had participated in two prior statewide studies (Blustein et al., 2016; Boehm et al., 2015). These parents had provided their email address for follow-up contact and had a son or daughter with intellectual and developmental disabilities (Blustein et al.). Among these direct email invitations, 142 were bounced back and thus undelivered.

Measures

I asked parents to complete a collection of measures addressing family quality of life and a variety of factors that may be associated with this construct, including relationships, spirituality, child and family demographics. (a print version of the data collection tool is included in Appendix A).

Family Quality of Life

I assessed family quality of life using the Beach Center Family Quality of Life Scale (FQOL; Beach Center on Disability, 2005). The scale measures a respondent's level of satisfaction with different aspects of family life that may contribute to overall quality of life for a family. The initial scale was developed through a process of extensive literature reviews, focus groups, and interviews with individuals with disabilities and their family members as well as service provider professionals (Poston et al., 2003). The original ten-domain, 112-item scale was piloted with 1,197 individuals (i.e., parents and other family members) from within 459 families of children whose disabilities ranged from mild to very severe. The scale was then reduced to five domains (i.e., Family Interaction, Parenting, Emotional Well-Being, Physical/Material Well-Being, and Disability-Related Supports) using factor analysis (Park et al., 2003). Some items were further refined by administering the scale to 488 families of children with disabilities (Hoffman, Marquis, Poston, Summers, & Turnbull, 2006). The final measure's five domains included 25 individual items (see Table 3 for items). Response options are on a 5-point, Likert-type scale ranging from 1 = *very dissatisfied* to 5 = *very satisfied*. A total score is derived by using the overall mean score for all 25 items. Domain scores are derived by using the mean of the items within each domain. Higher scores reflect higher FQOL. Hoffman et al. (2006) reported an overall Cronbach's alpha for the scale of .88 with significant test-retest reliability after three months for a subsample of participants. Furthermore, convergent validity was tested between FQOL subscales and relevant existing measures. The Family Interaction domain was correlated ($r = .68, p < .001$) with the Family APGAR (Smilkstein, Ashworth, & Montano,

1982), a 5-item measure of family functioning and the Physical/Material Well-Being domain was correlated ($r = .60, p < .001$) with the Family Resource Scale (Dunst & Leet, 1987), a 30-item measure of various family resources.

For the 529 participants in this study, FQOL total and domain ratings were all significantly correlated (i.e., moderate to high positive correlations) with each other. Overall Cronbach's alpha was .95 for all 25 items and individual domain reliability was as follows: Family Interaction (.91), Parenting (.87), Emotional Well-Being (.86), Physical/Material Well-Being (.78), and Disability-Related Supports (.81). Consistent with Poston et al. (2003), I defined *family* in this measure's introduction as "people who think of themselves as part of your family (even though they may or may not be related by blood or marriage), and who support and care for each other **on a regular basis.**" I also asked respondents to think about family life over the past 12 months and to not focus on relatives (extended family) who were only involved in their family every once in a while.

Religion/Spirituality

I assessed two aspects of religion/spirituality by using one question about frequency of congregation attendance and one multidimensional measure of overall religiousness/spirituality. The question on frequency of congregation attendance was, "How often do you attend religious services?" Response options were 0 = *never*, 1 = *less than once a year*, 2 = *once or twice a year*, 3 = *several times a year*, 4 = *once a month*, 5 = *2-3 times a month*, 6 = *about weekly*, 7 = *weekly*, 8 = *several times a week*.

Systems of Belief Inventory. I assessed overall religiousness/spirituality (R/S) using the Systems of Belief Inventory (SBI-15R; Holland et al., 1998). This multidimensional measure

was developed to explore religion/spirituality within QOL, stress, and coping research (see Table 4 for items). The measure consists of a beliefs and practices subscale (10 items) including both cognitively-oriented beliefs (e.g., “One’s life and death follows a plan from God”) and behaviorally-oriented practices (e.g., “I pray for help during bad times”), as well as a social support subscale (5 items; “I seek out people in my religious or spiritual community when I need help”). Response options include either a respondent’s level of agreement with, or frequency of behavior described in, each statement on a 4-point, Likert-type scale. Specifically, response options for level of agreement include, 1 = *strongly disagree*, 2 = *somewhat disagree*, 3 = *somewhat agree*, 4 = *strongly agree*. Response options for frequency of behavior statements include, 1 = *none of the time*, 2 = *a little bit of the time*, 3 = *a good bit of the time*, 4 = *all of the time*. A total score is derived by using the overall mean score for all 15 items (range, 1-4) with higher ratings indicating higher degree of R/S.

The original measure was developed by an interdisciplinary team of health professionals and clergy through a four-step process. First, they generated 35 items reflecting four domains of R/S (i.e., existential meaning of life, ritual practices, relationship to supreme being, social support derived from individuals sharing similar beliefs) and piloted with 12 hospitalized patients with different sites and stages of cancer. Second, they added 19 questions to enrich and ensure equal coverage of each of the four hypothesized domains and administered to 50 outpatients with malignant melanoma. The third step involved validating the 54-item instrument by administering it to a convenience sample of 301 healthy individuals from both religious ($n = 69$; e.g., ministers, priests, nuns, rabbis) and lay communities ($n = 232$; e.g., agnostic, no religious affiliation). The SBI-54 demonstrated good internal consistency (Cronbach $\alpha = .97$) and a principal components analysis with varimax rotation resulted in a two factor solution. The

fourth step involved reducing the measure by using only items with loadings of .60 or greater resulting in the final two subscale structure which was correlated with the original SBI-54 ($r = .98, p < .001$). The overall SBI-15 demonstrated high internal consistency (Cronbach $\alpha = .93$) and demonstrated convergent, divergent, and discriminant validity as well as test-retest reliability (Holland et al., 1998). To make this measure applicable more broadly within the healthcare field, they changed two items with language related to dealing with “diagnosis” to focus on dealing with “illness.” In applying this measure outside the healthcare field, I modified these two questions by replacing the word “illness” with “stress.” This measure can discriminate between religiously diverse subjects within a mixed sample (Hall et al., 2008). Although this scale has been widely used within the healthcare field to assess R/S of both patients and their caregivers (e.g., cancer, multiple sclerosis, other chronic illnesses), it had not been used with a sample of parents of individuals with ID. For the 529 participants in this study, this scale demonstrated good internal consistency (Cronbach’s $\alpha = .95$).

Relationships

I assessed informal relationships by using two of the three subscales (i.e., family, friends) of the Multidimensional Scale of Perceived Social Support (MSPSS; Zimet, Dahlem, Zimet, & Farley, 1988; see Table 5 for items). The full instrument includes 12 items measuring amount of social support from three sources: family (MSPSS-Fa: 4 items), friends (MSPSS-Fr: 4 items), and significant other (4 items). The MSPSS has been widely used among diverse populations, including parents of children with IDD, and has consistently demonstrated strong psychometric properties (Hardan-Khalil & Mayo, 2015). Three distinct subscales were validated through both exploratory (Zimet et al.) and confirmatory factor analysis (Zimet, Powell, Farley, Werkman, &

Berkoff, 1990). Previous studies have used these individual subscales to examine various aspects of social support with either the family and friend subscales (e.g., Benson & Kersh, 2011) or the friends and significant other subscales (e.g., Mak & Kwok, 2010). This measure has been previously used among parents with sons or daughters with various disabilities, including ID (e.g., Peer & Hillman, 2012).

The two subscales I used—family and friends—have high internal consistency with Cronbach’s coefficient alpha values ranging from .81 to .90 for the family subscale and from .85 to .94 for the friends subscale (Dahlem, Zimet, & Walker, 1991; Zimet et al., 1988, 1990). Responses are provided on a 7-point, Likert-type scale ranging from 1 = *very strongly disagree* to 7 = *very strongly agree*. A subscale score is derived by calculating the mean score of the items within that subscale; higher scores reflect more perceived social support from family or friends. I excluded the significant other subscale to eliminate potential ambiguity regarding whether respondents were referring to relationships within or beyond the family system. For the 529 participants in this study, both subscales demonstrated good internal consistency—Cronbach’s alpha for the family subscale was .94 and the friend subscale was .94.

I assessed formal relationships by using the Family-Professional Partnership Scale (FPP; Summers et al., 2005; see Table 6 for items). This scale was developed through a qualitative study comprised of 33 focus groups and 32 individual interviews with family members of children with and without disabilities to identify the skills, behaviors, and attitudes essential to healthy relationships between parents and service providers (Blue-Banning, Summers, Frankland, Nelson, & Beegle, 2004). This study identified six domains (i.e., communication, commitment, equality, skills, trust, respect) developed into an initial measure consisting of 10 items per domain. This 60-item measure was administered to 291 parents with a son or daughter

with IDD, over three quarters of whom were between the ages of 5 to 18 (Summers et al.). Exploratory factor analysis resulted in a two-factor solution confirmed through administering the revised measure to 205 parents relatively similar to the initial field test (Summers et al.). The final measure consists of a Child-Focused Relationship subscale with 9-items relating to the ways professionals relate to the son or daughter with disability (e.g., “treats your child with dignity”) and a Family-Focused Relationship subscale with 9-items relating to the ways professionals relate to the family (e.g., “shows respect for your family’s values and beliefs”). The full 18-item measure demonstrated good internal consistency with Cronbach’s coefficient alpha value of .96, as did both child- and family-focused subscales (Cronbach’s $\alpha = .94$ and $.92$ respectively). Furthermore, both subscales were strongly correlated ($r = .94$) and can be used as a single measure of family-professional partnerships (Summers et al.).

Participants are asked to answer the 18 items in reference to the service provider with whom they have had the most contact in the past 6 months. One additional question for the respondent indicates the type of service provider (i.e., education, health care, related services, child care, service coordinator, other) referenced when responding to the 18 items. Responses are provided on a 5-point, Likert-type scale ranging from 1 = *very dissatisfied* to 5 = *very satisfied*. A total score is derived by using the overall mean score. Although this scale has been used to explore associations with FQOL among parents of children with disability being served by early childhood programs (Summers et al., 2007) and for children birth to 21 years with deaf-blindness (Kyzar, Brady, Summers, Haines, & Turnbull, 2016), it has not been used among families with adult children with disability. Given my broader age focus, I changed the term “child” to “son/daughter.” For the 529 participants in this study, this scale demonstrated good internal consistency (Cronbach’s $\alpha = .98$).

Individual Child Variables

I collected data on six demographics of the child with ID among participating parents: (a) age, (b) gender, (c) presence of disability, (d) disability severity, (e) support needs, and (f) behaviors. I measured age as a continuous variable in years. I measured gender dichotomously as male or female.

I determined the presence of disability with three questions, two of which came from the National Health Interview Survey (NIHS; Zablotsky, Black, Maenner, Schieve, & Blumberg, 2015). Collected by the U.S. Census Bureau on behalf of the Centers for Disease Control and Prevention, the NIHS has been used to monitor the health of the nation since 1957. Despite slight modifications in 2014, the exact wording for the question about ID has been consistent since 1997. “Did a doctor or health professional ever tell you that [child’s name] had an intellectual disability, also known as mental retardation?” The prevalence estimates for ID from this question have been reliable over time with good validity of slightly over 1% of people estimated as having ID. This is similar to ID prevalence findings from a meta-analysis of 52 population-based studies (Maulik, Mascarenhas, Mathers, Dau, & Saxena, 2011).

The second question assessed the presence of autism spectrum disorder from the same NIHS survey (i.e., “Did a doctor or health professional ever tell you that [child’s name] had autism, Asperger’s disorder, pervasive developmental disorder, or autism spectrum disorder?”). I modified both NIHS questions by adding *special education professional* as a possible source of diagnosis for ID and ASD. For the third disability question, I included a list of 15 common disability labels associated with ID (i.e., Angelman syndrome, Cerebral Palsy, Cornelia de Lang syndrome, Down syndrome, Edward’s syndrome, Fetal alcohol syndrome, Fragile X syndrome,

Klinefelter syndrome, Lesch-Nyhan syndrome, Patau's syndrome, Prader-Willi syndrome, Rett syndrome, Smith-Magenis syndrome, Williams syndrome, 5p- [cri du chat] syndrome). To be included in this study, parents had to respond *yes* to the question indicating ID or respond with at least one etiological indicator of ID.

I measured disability severity by using an overall measure of severity along with a support needs measure. Consistent with the four-level system used to describe ID severity level in the *Diagnostic and Statistical Manual of Mental Disorders, 5th Edition (DSM-5)* and the *International Classification of Diseases, 11th Revision (ICD-11)* (Schalock & Luckasson, 2015) and the severity measure used by other FQOL researchers (Hu et al., 2012; Wang et al., 2004), I measured overall severity by asking parents to describe their child's disability as either mild, moderate, severe, or very severe. I also assessed severity with a support needs measure adapted from Lee, Wehmeyer, Palmer, Soukup, and Little (2008) measuring the degree of support needed to function across five domains (i.e., home living, community and neighborhood activities, social activities, health and safety activities, advocacy activities). Degree of support is indicated by ratings on a 5-point, Likert-type scale ranging from 1 = *no support needed* to 5 = *total support needed* (cf., Boehm et al., 2015). Individual scores are derived by using the mean of all five items, with higher scores reflecting more support needed.

I measured challenging behaviors with the Behavior Problems subscale of the Scales of Independent Behaviors—Revised (SIB-R; Bruininks, Woodcock, Weatherman, & Hill, 1996). This scale measures problem behaviors from infancy to adulthood on a continuum from highly internalized maladaptive behavioral expressions to highly externalized ones. The items in this subscale were not changed from the original SIB and includes eight behaviors grouped into three domains: internalized behaviors (i.e., hurtful to self, unusual or repetitive habits, withdrawal or

inattentive behavior), externalized behaviors (i.e., hurtful to others, destructive to property, disruptive behavior), and asocial behaviors (i.e., socially offensive behavior, uncooperative behavior). When a parent indicates his or her child displays a given behavior, that parent is then asked to rate the frequency (1 = *less than once a month* to 5 = *1 or more times/hour*) and the severity (1 = *not serious* to 5 = *extremely serious*) of that behavior. Standardized algorithms (Bruininks et al., 1996) translate the frequency and severity ratings into an age-adjusted score that is subtracted from 100 to calculate a general maladaptive index score. Thus, lower scores (below zero) indicate more severe challenging behaviors. Descriptively, the scale also provides a severity profile (i.e., normal, marginally serious, moderately serious, serious, very serious). The Behavior Problems subscale is supported by both theory and empirical research and has demonstrated good reliability and validity across multiple studies, including people both with and without disability (Bruininks et al.).

Individual Parent Variables

I collected data on six variables related to demographics of participating parents: (a) age, (b) gender, (c) parent role, (d) race/ethnicity, (e) health status, and (f) education. I measured age as a continuous variable in years. I measured gender dichotomously as male or female and caregiver role as mother, father, grandparent, aunt/uncle, or other (please describe). I measured race/ethnicity by asking parents to identify all that apply: White (non-Hispanic), African American/Black, Latina/Latino/Hispanic, American Indian or Alaska Native, Asian, Other: _____ (please describe). I measured health status with the question, “How would you rate your health at the present time?” on a 5-point, Likert-type scale with response options ranging from 1 = *poor* to 5 = *excellent* (Idler & Benyamini, 1997). I measured parents’ highest level of

education using the following response options: some high school, high school degree, some college, 4 year degree, graduate/professional degree, or none of the above (please describe).

Family Unit Variables

I collected data on three variables related to the family unit: (a) total household size; (b) annual household income; and (c) disability-related public funding/support. I measured total household size by asking parents to report the total number of people living in the house at least a majority of the time. I measured income by asking whether overall household family income is either less than \$15,000, \$15,000 to 34,999, \$35,000 to 49,999, \$50,000 to 74,999, \$75,000 to 99,999, or \$100,000 or more. I used one *yes/no* question “Is your son or daughter with intellectual disability currently receiving any state or federally funded disability service benefits, funding, or services?” to assess whether the family received any public funding/support as a result of having a child with disability.

Data Collection

I began identifying recruitment partners in February 2016 and collected data from July through September of 2016. Parents who responded to a recruitment invitation were asked to complete a collection of measures online using either a professional Survey Monkey account or a 16-page printed version (by request). Nineteen printed surveys, along with a postage-paid return envelope were requested—13 completed surveys were returned. All data were exported into SPSS (Statistical Package for the Social Sciences). Data collected through the print version were manually entered online. All participants were entered into a random drawing to receive one of 40 gift cards valued at \$25 each.

Although the overarching project included a broader set of measures, this dissertation focuses specifically on family quality of life and the measures of social relationships, religion/spirituality, and additional predictor variables described previously. Prior to this study, I piloted all measures with a sample of 7 parents from both states with a son or daughter with ID ranging from 7 to 42 years. I asked for feedback on the content, clarity, and length of the measures. Feedback was positive with a few recommendations for minor wording changes for clarity.

Data Analyses

I used descriptive statistics and analysis of variance (ANOVA) to answer my first research question. I used ANOVAs to answer my second research question. I used correlations and regression analyses to answer my third research question. These analyses are described after first addressing the handling of missing data and assumption checking.

Missing Data and Methods of Imputation

For the correlation and regression analyses (but not the descriptive analyses), I imputed missing data according to the following rules. For participants who were missing items needed to compute a scale score (i.e., FQOL domains, support needs, behaviors, family relationships, friend relationships, professional relationships, religiousness/spirituality), if they had 75% or more valid items on that scale each participant's own median on other items of the scale was imputed for the missing value. The mode was substituted for nominal variables (i.e., parent race/ethnicity, education, household size, household income, parent role, public funding/support) that had fewer than 5% missing values. The median was substituted for ordinal/continuous

variables with fewer than 5% missing values (i.e., professional relationships, religiousness/spirituality).

Checking Assumptions

Even though large samples are relatively robust against violations of the assumption of normally distributed data, I screened the residuals to ensure there were no gross violations. Residuals are the differences between the predicted and obtained values of the dependent variable. The residual plot enabled me to compare the predicted versus obtained FQOL ratings and these “errors” were normally distributed and thus I did not screen individual variables for normality (Tabachnick & Fidell, 2007). To check for evidence of multicollinearity, I examined bi-variate associations for all variables and conducted SPSS multicollinearity diagnostics. Tolerance ratings were all above .45 (variance inflation factors were all lower than 2.22). Assumptions of normally distributed data and lack of multicollinearity were both met.

Descriptive Statistics

To answer the first research question (*How do parents of individuals with ID describe their FQOL?*) I used descriptive statistics (i.e., mean, frequency, percentage) to summarize all measures by overall scale and, when relevant, item- and subscale-levels. Additionally, I used a repeated measures ANOVA with follow up pair-wise comparisons with Bonforreni adjustments for multiple comparisons to compare the five FQOL domain means.

Analyses of Variance

To answer research question two (*Do these FQOL ratings differ based on disability, age, or regional differences?*) I conducted three ANOVAs to compare FQOL ratings by disability, age, and region. FQOL descriptive findings among families impacted by ID are often reported without differentiating who have an additional diagnosis of ASD. Thus, I compared FQOL ratings for parents whose child also had a diagnosis of ASD versus those whose child did not. Family systems are impacted when a child exits the school system and launches into adulthood. For families whose child has ID, this life-stage transition may include unique family challenges and opportunities (Taylor, Burke, Smith, & Hartley, 2016). To consider the possible role of this life-stage transition of exiting the school system on FQOL, I compared FQOL ratings for parents whose child was up through age 21 versus those whose child was age 22 or older. I chose this cut score based on age 21 as the final year of federal eligibility for special education services under IDEA. Because performance and systemic factors may vary in different regions, I compared FQOL ratings for parents living in Illinois versus Tennessee. For each significantly different mean comparison, I calculated an effect size using a Cohen's d statistic (i.e., $\delta = 2t/\sqrt{df}$).

Correlations and Regression Analyses

To answer research question three (*What demographic (i.e., child, parent, family), religious/spiritual, and relational factors predict FQOL?*) I computed Pearson correlation coefficients to examine associations between all variables (see Table 7). Because four variables were dichotomous (i.e., ASD, parent role, race/ethnicity, and public funding/support) I used point biserial correlations when one variable was dichotomous and a phi coefficient when both were dichotomous. I then used linear multiple regression analyses in three steps to examine the

extent to which child-, parent-, family-, religious/spiritual-, and relationship-factors predicted parents' overall FQOL ratings (see Table 8). The three steps, or blocks of predictor variables, are described below.

The first block contained demographic variables for which I wanted to control (i.e., child-, parent-, family-factors). Specifically, the first block contained individual child (i.e., age, ASD, disability severity, support needs, behaviors), individual parent (i.e., parent role, race/ethnicity, education, health status), and family-level (i.e., household size, household income, public funding/support) variables. These demographic predictor variables were coded in the following ways (all variables were based on a single item question unless otherwise specified): child age (continuous variable), ASD (0 = no ASD diagnosis, 1 = ASD diagnosis), disability severity (range, 1-4), support needs (5 items, range, 1-5), behaviors (8 behaviors/16 items, range, -62-10), parent role (0 = not mother, 1 = mother), race/ethnicity (0 = not White only, 1 = White only), parent education (range, 1-6), health status (range, 1-5), household size (continuous variable), household income (range, 1-6), and public funding/support (0 = not receiving, 1 = receiving).

A second block of predictors added religious/spirituality variables to the previous demographics block. Specifically, these additional predictors included overall religiousness/spirituality (15 items, range, 1-4) and frequency of congregation attendance (range, 0-8).

The third block of predictors added relationship variables (i.e., family, friends, professionals) to the previous two blocks of predictors. Specifically, these relationships included family relationships (4 items, range, 1-7), friend relationships (4 items, range, 1-7), and professional relationships (18 items, range, 1-5).

To evaluate the relative value of predictors in accounting for the variance in FQOL ratings, I examined R^2 , change in R^2 , beta coefficients, and semipartial, or part, correlations. Specifically, I examined R^2 for all three steps in the regression for statistical significance to evaluate the amount of variance in FQOL ratings accounted for by each block. Adjusted R^2 adjusts for the number of predictors and only increases if the added predictors improve the model beyond what would be expected by chance (Tabachnick & Fedell, 2013). I also examined the change in R^2 and whether the amount of change was significant in order to evaluate whether the increased amount of predictive value added by the additional block of IVs was significant. I examined beta weights (standardized multiple regression coefficients) and semipartial (i.e., part) correlations to determine the relative value of each predictor variable in each model. The unique predictive value for a given variable is the percentage of variance in the FQOL outcome variable accounted for by that predictor variable over and above the variance explained by the remaining predictors in the regression model.

CHAPTER 3

RESULTS

Q1: How Do Parents of Individuals with ID Describe Their FQOL?

Overall, parents indicated satisfaction ($M = 3.84$, $SD = 0.68$, range 1-5) with their family quality of life (see Table 3) with 71.8% of parents reporting being either satisfied or very satisfied. Parents rated their degree of satisfaction most highly in the domain of Physical/Material Well-Being ($M = 4.11$, $SD = 0.71$), followed by Family Interaction ($M = 4.00$, $SD = 0.76$), Disability-Related Supports ($M = 3.83$, $SD = 0.83$), and Parenting ($M = 3.81$, $SD = 0.75$). Parents gave the lowest ratings to the domain of Emotional Well-Being ($M = 3.30$, $SD = 1.02$). To determine whether the domain means were significantly different from each other, I conducted a repeated-measures ANOVA and results confirmed a statistically significant difference among the five domain means. Multiple follow-up paired t -tests confirmed all domains were significantly different from each other ($p < .001$) except Parenting and Disability-Related Supports ($p = .483$).

Although parents reported satisfaction across most individual items, Emotional Well-Being ratings were consistently low (see Table 3). For example, all four items in this domain were the scale items with the largest percentages (ranging from 24.8% to 38.8%) of parents who reported being *dissatisfied* or *very dissatisfied*.

Q2: Are There Differences in FQOL Ratings Based on Disability, Age, or Region?

Parents of individuals with ID only reported significantly higher overall FQOL ratings ($M = 4.00$, $SD = 0.64$) than parents of individuals with both ID and ASD ($M = 3.62$, $SD = 0.68$), $F(1, 494) = 40.09$, $p < .001$. Cohen's d was 0.57, indicating a moderate effect size. Parents of individuals age 22 or older reported similar overall FQOL ratings ($M = 3.91$, $SD = 0.67$) than parents of younger children age 21 or below ($M = 3.79$, $SD = 0.69$), $F(1, 494) = 3.87$, $p = .050$. Cohen's d was 0.18, indicating a small effect size. Overall FQOL ratings among parents living in Illinois ($M = 3.87$, $SD = 0.66$) were similar to those living in Tennessee ($M = 3.81$, $SD = 0.69$), $F(1, 494) = 0.92$, $p = .337$. Cohen's d was 0.09, indicating a very small effect size.

Q3: What Factors Predict FQOL Ratings?

Prior to running regression analyses, I examined the correlations among all variables (see Table 7). The strongest positive associations with FQOL satisfaction ratings were the three types of relationships (Family, $r = .68$, $p < .001$; Friends, $r = .56$, $p < .001$; Professionals, $r = .49$, $p < .001$). The presence of challenging behaviors had the next strongest positive association ($r = .46$, $p < .001$). The presence of an additional diagnosis of ASD had the strongest negative association with FQOL satisfaction ratings ($r = -.26$, $p < .001$).

I used three nested linear regression analysis models to consecutively examine demographic, religious/spiritual, and relational factors contributing to overall FQOL. Because the five FQOL domain scores were highly correlated with each other (r s between .79 and .92), I only report predictor variables' association with overall FQOL.

Individual and Family Factors

The first block of demographic variables included child (i.e., age, ASD, disability severity, support needs, behaviors), parent (i.e., role, race/ethnicity, education, health status), and family-level (i.e., household size, household income, public funding/support) variables. The regression model accounted for 33.4% of the variance in parents' satisfaction ratings, $R^2 = .334$, $F(12, 516) = 21.60$, $p < .001$. As shown in Table 8, higher FQOL ratings were independently significantly predicted by less challenging behaviors, less intensive support needs, better parent health, greater household income, and receiving public funding/support.

Religious/Spiritual Factors

The second block added overall religiousness/spirituality and frequency of congregation attendance to the list of demographic predictors. This added 3.0% predictive value (i.e., change in $R^2 = .030$, $p < .001$). This regression model accounted for 36.4% of the variance in parents' satisfaction ratings, $R^2 = .364$, $F(14, 514) = 21.02$, $p < .001$. As shown in Table 8, greater overall religiousness/spirituality independently predicted higher FQOL ratings; frequency of congregation attendance did not. Other predictors in this model were consistent with the first block with the exception that child support needs was no longer a significant predictor.

Relational Factors

The final block added both informal (i.e., family, friends) and formal (i.e., professional) relationships to the list of demographic and religious/spiritual predictors. which added 26.6% predictive value (i.e., change in $R^2 = .266$, $p < .001$). This regression model accounted for 63.0% of the variance in parents' satisfaction ratings, $R^2 = .630$, $F(17, 511) = 51.10$, $p < .001$. As shown

in Table 8, stronger family, friend, and professional relationship ratings independently predicted higher FQOL ratings. Although the magnitude of predictive value for each IV changed in this full model, the variables significantly predicting FQOL ratings were consistent with previous blocks including the reemergence of child support needs as a significant predictor.

CHAPTER 4

DISCUSSION

Improving quality of life for families impacted by ID has been a growing area of research for the past three decades. Understanding FQOL among these families, and the factors that shape it, can inform the design of better policies and the delivery of better practices focused on improving FQOL. This study included the largest sample of parents of individuals with ID within the United States published to date focusing on FQOL. Previous research included smaller sample sizes and typically focused more narrowly on a particular age-range and/or included greater diversity of disability types. Among the 529 parents included in this study, experiences across the full lifespan of their daughters and sons are represented. Furthermore, although all the parents reported having received an ID diagnosis for their child, a majority did not also have a co-occurring diagnosis of ASD. This study provides insight into FQOL perceptions for families impacted by ID across the lifespan. Findings will be discussed in terms of describing parent FQOL ratings and the factors associated with variability among these ratings.

Family Quality of Life and Disability

Within this large sample of parents, family quality of life satisfaction was relatively high. This profile stands in contrast to the “disability as tragedy” narrative that has historically dominated most assumptions about having a son or daughter diagnosed with ID (Singer & Wang, 2014). Although parenting any child involves stress, and parenting a child with ID may involve additional stressors, parents of a child with ID are not relegated to a poor quality of life

(Hastings, 2016). This should be especially good news to newer parents whose dreams for their child and the future well-being of their family are tested and reshaped in light of an ID diagnosis and the potential implications. Doctors and disability-related professionals should examine their own assumptions about the impact of disability and avoid reinforcing negative stereotypes. Along with accurate information, effective interventions, and appropriate referrals professionals should consistently reinforce messages of hope and encouragement to parents about the quality of their future family life. These messages of hope for a satisfying family quality of life should spawn not only from a professional's idealism or good intentions but from positive empirical evidence of parent satisfaction.

This finding of moderately high ratings of overall FQOL is robust both within (e.g., McFelea & Raver, 2012) and beyond (e.g., Foley et al., 2014; Vilaseca et al., 2015) the United States. Although ratings of overall FQOL have tended to be relatively high, variability exists among families. For example, parents in this study reported less satisfaction in the domain of emotional well-being (EWB). Identifying lower FQOL domains could become the focus for developing targeted interventions to support parents in that domain area to help improve overall FQOL. This finding of lower EWB ratings is relatively consistent across much of the FQOL literature (e.g., Boehm et al., 2015; Hoffman et al., 2006). However, there are exceptions. For example, Giné and colleagues (2015) found parent FQOL ratings of emotional well-being (EWB) to be relatively high among 266 families of both younger and adult children with ID. Although *t*-tests were not done to compare ratings, EWB was among the top three (of seven) FQOL domains and were higher than the overall FQOL mean (5-point scale) for the 144 families with children with ID up to 18 years (EWB = 3.97 versus Overall = 3.86) and the 122 families with adult children with ID over 18 years of age (EWB = 4.15 versus Overall = 3.98). Thus,

although the moderate overall FQOL ratings for families impacted with ID is consistent with other overall FQOL findings, it is less clear what accounts for variability among these ratings.

Although the presence of an additional ASD diagnosis did not predict FQOL ratings, there was a significant difference between overall FQOL ratings of families with and without this comorbid diagnosis. This difference, however, was between varying degrees of satisfaction rather than neutrality or dissatisfaction. The ID plus ASD group still reported levels of satisfaction slightly above neutrality (i.e., not *dissatisfied* or *very dissatisfied*). It is likely that the overall mean difference reflects the impact of risk factors associated with ASD such as the presence of challenging behaviors. Once the effect of other child, parent, and family factors were accounted for, the presence of an ASD diagnosis was no longer predictive of lower FQOL ratings. Professionals delivering an initial comorbid diagnosis to parents should also convey messages of hope and encouragement that the quality of their future family life can still be satisfying while also partnering with them to address the family's unique challenges and specific needs.

Relational Dimension of Life

Addressing the relational dimension of a parent's life significantly improved the ability to predict FQOL ratings. Specifically, including three types of relationships in the final regression model (i.e., family, friends, professionals) accounted for over 26% more variability in overall FQOL satisfaction with better relationship ratings associated with higher FQOL ratings. Policy makers and practitioners seeking to improve the lives of families impacted by ID should remember that relationships matter and work to support parents in having healthy ones. A promising initiative focused on helping individual states improve their policies and practices to

support families well is the National Community of Practice (supportstofamilies.org) encompassing a growing number of states working and learning together to improve family outcomes. Their growing collection of resources and tools (www.lifecoursetools.com) offer many ways to identify and improve the relationships that matter most to parents. For example, there are tools to develop a long-term family vision with a focus on six life domains—one of which is Social & Spirituality (the others include: Daily Life and Employment, Community Living, Safety and Security, Healthy Living, and Citizenship and Advocacy). A professional can use this tool to help a parent envision the kind of relationships they want for themselves and their family. Furthermore, the Integrated Services and Supports tool can be used to identify five types of supports—one of which is Relationship-Based support (the others include: Technology, Eligibility Specific, Personal Strengths and Assets, and Community-Based). These tools draw attention to the social domain (i.e., relational dimension) of life and can be used to focus attention, planning, and action to identify and cultivate meaningful parent relationships. Focusing on these relationships in targeted and individualized ways could go a long way toward enhancing FQOL.

Family Relationships

Family members were the types of people (i.e., relationship types) most notably associated with FQOL satisfaction. Stronger family relationships were associated with higher FQOL. Although questions about family relationships did not distinguish between different family roles, these relationships could be with one's spouse or child(ren) as well as extended family members such as parents and siblings (i.e., the grandparents, aunts, and uncles of the child with ID). Each member of the family, whether they live together or not, may play a unique role

in a parent’s life—for better or worse. For example, improving spousal relationship quality may help improve individual and family quality of life. Norlin and Broberg (2013) found spousal relationship quality predicted individual well-being among parents of children with ID under 10 years old. Weitlauf, Vehorn, Taylor, and Warren (2012) found the quality of the spousal relationship buffered the effects of parenting stress on depression among mothers of young children recently diagnosed with ASD. The finding that spousal relationships are associated with individual well-being and help shape FQOL highlight the interdependence of family relationships whereby support focused more directly toward helping one family member can indirectly support other family members. In other words, efforts to support parents (or siblings) directly may have a positive indirect impact on other members of the family and improve overall FQOL (Erel & Burman, 1995). Smith-Bird and Turnbull (2005) found a similar linkage between individual and family outcomes and issued the challenge to “[b]roaden the scope of intervention to the entire family [because it] directly affects family quality of life” (p. 179). Thus, efforts to support individual relationships within a family system may serve to buoy up family quality of life for every family member.

Friend Relationships

Beyond the family system, friends are important people in the lives of parents with a son or daughter with ID (Boehm & Carter, 2016). These friendships are typically described as *informal* relationships. Whereas informal relationships are usually defined as individuals who are not paid to be in a parent’s life, formal relationships are those professionals (e.g., their child’s doctor, teacher, or therapist) involved with a family to render a disability-related service (Samuel, Hobden, LeRoy, & Lacey, 2012). Although much of the social support literature blurs

distinctions between family and non-family informal relationships (e.g., McConkey, Truesdale-Kennedy, Chang, Jarrah, & Shukri, 2008), this study isolated non-family informal relationships and found they uniquely contributed to FQOL. Furthermore, while parents reported the lowest ratings on the individual item about receiving emotional support from family relationships ($M = 4.79$), they reported the highest ratings on the corresponding item about sharing joys and sorrows with friends ($M = 5.06$). Thus, friendships are important as relationships where emotional support can be meaningfully exchanged and FQOL improved. Although other supports may also be exchanged within these informal relationships (e.g., information, child care), previous research has highlighted the significance of emotional support (Boehm & Carter, 2016). Family support policies and practices that enable parents to have time to invest in these informal relationships—exchanging emotional and other types of support—may be especially important. Respite care opportunities, for example, may help parents invest quality time with friends—as well as other family members (e.g., spouse or other children). Additionally, opportunities for parents to participate in a parent support group to develop relationships with other parents could also help improve FQOL. Additional research should explore interventions that may improve informal relationships, such as respite programs and other family support practices, and how these improved relationships may help improve FQOL.

Professional Relationships

Among all variables examined in this study, formal relationships were the second strongest predictor of FQOL. This finding highlights the important role professionals play in families' lives. There has been a growing focus on understanding parent-professional partnerships (e.g., Blue-Banning et al., 2004) and their implications for FQOL (e.g., Kyzar et al.,

2016). The role of professionals is to offer various types of supports and services to parents who have a child with disability such as information/education, technical skills, specific therapies or interventions, and referrals to other professionals. However, the relationships professionals cultivate with parents may offer something beyond these more tangible supports. In other words, there may be something about the quality of the relationship itself, beyond merely the services rendered, that matters. Professionals should thus adopt a relationally-driven approach rather than merely a task-driven one where services are rendered but relationships are also nurtured. Additional research should consider the relational aspects of professional partnerships—beyond merely the tangible supports and technical services rendered—that may play a supportive function for parents as well as potentially contribute to job satisfaction for the professional. Additionally, researchers should explore ways to strengthen parent-professional relationships as a way to improve FQOL and other parent outcomes.

Sacred Dimension of Life

Addressing the sacred dimension of parents' lives also improved the ability to predict FQOL ratings. Specifically, adding overall religiousness/spirituality and frequency of congregation attendance to the initial individual- and family-level demographic variables, accounted for 3% more variability in overall FQOL satisfaction. Furthermore, even after the relational variables were added into the final regression model, overall R/S continued to be a significant predictor ($r = .07$)—with predictive value similar to child support needs, parent health status, household income, and friend relationships ($r_s = -.07, .10, .07, .07$ respectively)—with higher R/S ratings associated with more satisfying FQOL. This finding adds to the growing area of research focusing on the intersection of disability and faith/religion/spirituality (e.g., Carter,

2013; Zhang & Rusch, 2005). Specifically, this finding suggests the importance of the sacred dimension of life and how it contributes to the way a parent perceives the quality of family life. The sacred dimension of life may include beliefs, practices, as well as potential relationships available to parents as a result of their spiritually oriented involvement. Interestingly, within the measure of overall R/S, all items on the Beliefs and Practices subscale were higher than all items on the Social Support subscale. This difference highlights the strength of parent agreement and greater reported frequency of sacred beliefs and practices. Furthermore, among all 15 items parents most strongly agreed with the statement, *I feel certain that God in some form exists*, which could be construed as a belief, or an issue of faith. Although how one lives (i.e. practices) helps to shape quality of life, beliefs may be foundational. Emerging evidence suggests the significant role of the strength of one's religious beliefs in shaping their FQOL. For example, Boehm and colleagues (2015) reported greater strength of religious faith predicted higher FQOL ratings among parents of transition age youth and young adults with ID and/or ASD even after controlling for child behaviors, support needs and other child and family factors. Continued research to understand how various aspects of the sacred—including aspects of one's faith or religious beliefs— may help shape FQOL, can help inform practitioners' efforts to support parents in holistic ways. For example, education professionals serving youth and young adults are positioned to help families identify and include faith-oriented goals into transition planning. Goals such as getting involved in a congregation or volunteering with a local ministry could provide students with ways to enrich social opportunities and expand vocational opportunities for post-school community life. Furthermore, professionals charged with supporting and serving adults with ID are also positioned to help their clients live self-determined lives by ensuring aspects of their faith are honored and supported.

Limitations and Research Implications

Several limitations to this study suggest opportunities for future research. First, this study relied on only one parent's self-reported perceptions of FQOL. The definition of FQOL involves "a dynamic sense of well-being of the family *collectively* and subjectively defined and informed by its *members*, in which individual and family-level needs interact" (Zuna et al., 2010, p. 262, italics added). One parent's perceptions of FQOL do not necessarily reflect a *collective* view and those perceptions do not constitute a view informed by *members* but only by one member. Accordingly, the findings may not accurately or adequately describe the overall quality of a family's life or the factors associated with FQOL. Although much of the FQOL research has relied on the main caregiver—usually the mother—to describe FQOL, perceptions of other family members such as spouse, the individual with ID, and other children within the family should be considered (Zuna, Brown, & Brown, 2014). Gathering these multiple perspectives within families will require collecting and analyzing data from these different sources. Furthermore, whether FQOL can best be described through individual or aggregate subjective perceptions of family members and whether objective measures (e.g., observations) should also be included remains unclear (Zuna et al., 2010).

Second, responding parents may not be representative of all parents impacted by ID in the United States. Although I was intentional about sampling from two regions of the country, seeking input from parents who were less affluent and had fewer connections to formal services, and involving parents who did not have access to the internet, it is unclear how responding parents differ from those who never heard about the study or opted not to participate. Additionally, there was a large proportion of parents whose child had both ID plus ASD reflecting perhaps twice as high as prevalence estimates would suggest (Tonnesen et al., 2016).

Although I focused analytic efforts to distinguish the unique contribution of ASD, the reasons for this sampling bias are unclear. Future research should distinguish between ID only and comorbid ASD to improve the ability to understand FQOL among heterogeneous families impacted by ID.

Third, although findings of this study highlight the importance of the relational dimension of life to shaping FQOL, the three relationship measures used in this study have limited scope. Relationships are a multidimensional construct. For example, Boehm and Carter (2016) reported findings in terms of three relationship dimensions from a systematic literature review of 52 studies addressing informal relationships. Specifically, they reported findings on relationship *affiliations* (i.e., the types of people with whom parents had relationships and the amount of contact they had), *perceptions* (i.e., parents' views of these relationships such as degree of availability or helpfulness), and *supports exchanged* (i.e., the specific types of resources given and/or received within these relationships such as emotional, financial, or informational). The items used to measure family (4 items), friend (4 items), and professional relationships (18 items) all had a history of strong psychometric properties, however, their dimensionality has not been evaluated. In other words, findings from this study demonstrate parent relationships are important in their lives and the strength of association with FQOL differs based on the type of relationship (i.e., family, friend, professional). However, it remains unclear what dimension of these relationships is most influential or how different dimensions may function in a parent's life. Future research should explore the association between relationships and FQOL by drawing on other psychometrically sound relationship measures (e.g., López & Cooper, 2011) and by creating new ones with specified, and psychometrically verified, dimensionality. Furthermore, attention should be given to explore specified relationship dimensionality and how each may function differently in parents' lives.

Conclusion

This large-scale study examined the quality of life for families with a member with intellectual disability and the factors that shape FQOL. Participants included 529 parents of both children and adults with ID from two regions of the United States. Despite a common assumption that having a child with ID constitutes a family tragedy, the parents in this study reported overall satisfaction with their FQOL. Furthermore, findings highlight the significant role of parent relationships with family, friends, and professionals and how these different types of relationships shape their perceptions of FQOL. Additionally, parents' overall religiousness/spirituality was a significant predictor of FQOL, even after controlling for individual and family factors, with higher R/S ratings associated with higher FQOL. Future research should continue to explore the power of social relationships, and the sacred dimension of life, in shaping FQOL. Additionally, practitioners should support families in cultivating strong relational networks, and incorporating their sacred beliefs and practices into their daily and weekly rhythms of life, as ways to promote higher FQOL among families impacted by ID.

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Table 1
Demographics of Responding Parents/Families

Variable	Total n (%)
Relationship to son/daughter with ID	
Mother	460 (87.0)
Father	42 (7.9)
Sibling	12 (2.3)
Grandparent	8 (1.5)
Other (i.e., cousin, foster, guardian, aunt/uncle)	6 (1.1)
Information not provided	1
Age	
20's	7 (1.3)
30's	71 (13.5)
40's	111 (21.1)
50's	194 (37.0)
60's	105 (20.0)
70 or above	37 (7.0)
Information not provided	4
Household size	
Living alone	15 (2.8)
Two	87 (16.5)
Three	169 (32.0)
Four	146 (27.7)
Five	67 (12.7)
Six or more	44 (8.4)
Information not provided	1
Race/ethnicity^a	
White (non-Hispanic)	464 (87.7)
African American/Black	37 (7.0)
Latina/Latino/ Hispanic	17 (3.2)
Asian/Asian American	10 (1.9)
American Indian or Alaska Native	2 (0.4)
Other (e.g., Middle Eastern)	3 (0.6)
Information not provided	1
Highest level of education completed	
High school degree	50 (9.5)
Some college	101 (19.1)
Two-year degree	55 (10.4)
Four-year degree	157 (29.7)
Graduate/professional degree	165 (31.2)
Information not provided	1
Annual household income	
Less than \$15,000	12 (2.4)
\$15,000 – \$34,999	72 (14.2)
\$35,000 – \$49,999	58 (11.4)
\$50,000 – \$74,999	108 (21.3)
\$75,000 – \$99,999	85 (16.8)
\$100,000 or more	172 (33.9)
Information not provided	22
Frequency of congregation attendance	
Never	56 (11.1)
Less than once a year	48 (9.5)
Once or twice a year	41 (8.1)
Several times a year	61 (12.1)
Once a month	23 (4.6)
Two to three times a month	49 (9.7)
About weekly	40 (7.9)
Weekly	141 (27.9)
Several times a week	46 (9.1)
Information not provided	24

Note. Percentages are based on the number of participants who completed the given item.

^a Response instructions included *check all that apply* thus total is more than 100%.

Table 2
Demographics of Sons and Daughters with Intellectual Disability

Variable	Total <i>n</i> (%)
Gender	
Male	335 (63.9)
Female	189 (36.1)
Information not provided	5
Age	
Birth to 9	86 (16.3)
10 to 19	158 (29.9)
20 to 29	163 (30.8)
30 to 39	75 (14.2)
40 to 49	35 (6.6)
50 or above	12 (2.3)
Information not provided	0
Additional ASD diagnosis	
Yes	211 (39.9)
No	318 (60.1)
Information not provided	0
Disability severity	
Mild	72 (13.6)
Moderate	295 (55.8)
Severe	132 (25.0)
Very severe	30 (5.7)
Information not provided	0
Degree of overall support needed <i>M</i> (<i>SD</i>) ^a	3.71 (0.94)
Level of seriousness of behaviors ^b	
Normal	294 (55.6)
Marginally serious	89 (16.8)
Moderately serious	48 (9.1)
Serious	34 (6.4)
Very serious	16 (3.0)
Information not provided	48

Note. Percentages are based on number of participants who completed the given item.

ASD = autism spectrum disorder

^aRange 1-5 in measure adapted from Lee, Wehmeyer, Palmer, Soukup, and Little (2008). ^bBehavior Problems subscale of the Scales of Independent Behaviors—Revised.

Table 3
Parent Responses on Beach Center Family Quality of Life Scale Items

Domain/Item	Missing	Percentage of responses					<i>M (SD)</i>
		Very Dissatisfied (1)	Dis satisfied (2)	Neither (3)	Satisfied (4)	Very Satisfied (5)	
Family Interaction							4.00 (0.76)
My family members show that they love and care for each other.	1	1.5	4.0	6.4	43.6	44.5	4.26 (0.86)
My family enjoys spending time together.	0	1.5	6.8	5.9	48.2	37.6	4.14 (0.91)
My family members talk openly with each other.	0	1.7	9.5	10.6	47.8	30.4	3.96 (0.97)
My family members support each other to accomplish goals.	1	1.3	8.3	11.9	51.7	26.7	3.94 (0.91)
My family is able to handle life's ups and downs.	2	1.7	7.8	13.3	56.2	21.1	3.87 (0.89)
My family solves problems together.	1	2.7	9.3	14.4	52.3	21.4	3.80 (0.97)
Parenting							3.81 (0.75)
My family members teach my son(s) and/or daughter(s) how to get along with others.	2	1.3	3.8	16.7	49.1	29.0	4.01 (0.85)
Adults in my family teach my son(s) and/or daughter(s) to make good decisions	0	1.9	4.7	14.0	50.1	29.3	4.00 (0.89)
Adults in my family know other people in my son(s) and/or daughter(s) lives (i.e., friends, teachers, etc.).	3	2.1	7.6	12.4	53.8	24.1	3.90 (0.92)
My family members help my son(s) and/or daughter(s) learn to be independent.	2	2.1	7.6	17.8	46.5	26.0	3.87 (0.96)
Adults in my family have time to take care of the individual needs of every son and/or daughter.	1	3.2	15.9	14.8	48.5	17.6	3.61 (1.05)
My family members help my son(s) and/or daughter(s) with schoolwork and activities.	6	6.3	11.9	27.9	39.2	14.7	3.44 (1.08)
Emotional well-being							3.30 (1.02)
My family members have some time to pursue their own interests.	1	4.2	20.6	12.7	41.1	21.4	3.55 (1.16)
My family members have friends or others who provide support.	0	8.2	19.4	18.2	38.0	16.3	3.35 (1.20)
My family has the support we need to relieve stress.	3	8.4	22.8	19.4	33.1	16.3	3.26 (1.22)
My family has outside help available to us to take care of special needs of all family members.	0	14.6	24.2	16.6	31.9	12.7	3.04 (1.29)
Physical/material well-being							4.11 (0.71)
My family gets medical care when needed.	3	2.1	4.0	2.9	41.1	50.0	4.33 (0.88)
My family feels safe at home, work, school, and in our neighborhood.	2	0.9	2.3	4.4	47.4	45.0	4.33 (0.75)
My family gets dental care when needed.	0	4.3	6.6	6.0	40.6	42.3	4.10 (1.06)
My family members have transportation to get to the places they need to be.	0	3.0	10.2	6.6	44.4	35.7	4.00 (1.05)
My family has a way to take care of our expenses.	2	4.4	10.6	12.0	49.5	23.5	3.77 (1.06)
Disability-related supports							3.83 (0.83)
My family member with a disability has support to accomplish goals at home.	0	1.7	6.8	9.8	47.8	33.8	4.05 (0.93)
My family has good relationships with the service providers who provide services and support to our family members with a disability.	0	3.2	6.4	13.8	46.1	30.4	3.94 (0.99)
My family member with a disability has support to accomplish goals at school or workplace.	3	4.4	10.1	11.6	48.3	25.7	3.81 (1.07)
My family member with a disability has support to make friends.	2	6.5	16.1	18.4	37.6	21.4	3.51 (1.18)

Note. Missing column represents the number of people with missing data on that item. Percentages of responses are based on the number of participants completing a given item.

Table 4

Parent Responses on System of Belief Inventory (SBI-15R) Scale Items

Subscale/Item	Missing	Percentage of responses				<i>M (SD)</i>
		1	2	3	4	
Beliefs and practices						
I feel certain that God in some form exists.	19	3.5	4.3	10.0	82.2	3.71 (0.71)
One's life and death follows a plan from God.	24	9.7	8.3	25.5	56.4	3.29 (0.98)
I have experienced a sense of hope as a result of my religious or spiritual beliefs.	20	10.0	7.3	27.9	54.8	3.28 (0.97)
I pray for help during bad times.	21	7.9	13.8	25.2	53.1	3.24 (0.96)
I have experienced peace of mind through my prayers and meditation.	21	8.7	6.5	37.2	47.6	3.24 (0.91)
Religion is important in my day-to-day life.	19	14.9	7.1	24.1	53.9	3.17 (1.09)
During times of stress, my religious or spiritual beliefs have been strengthened.	22	9.9	11.6	31.6	46.9	3.16 (0.98)
I believe God will not give me a burden I cannot carry.	24	14.7	11.3	23.8	50.3	3.10 (1.09)
Prayer or meditation has helped me cope during times of stress.	18	7.8	19.4	30.3	42.5	3.07 (0.96)
I believe God protects me from harm.	25	11.7	13.3	32.1	42.9	3.06 (1.01)
Social support						
I enjoy attending religious functions held by my religious or spiritual group.	23	15.0	12.3	33.4	39.3	2.97 (1.06)
I enjoy meeting or talking often with people who share my religious or spiritual beliefs.	22	11.4	28.0	28.8	31.8	2.81 (1.01)
When I need suggestions on how to deal with problems, I know someone in my religious or spiritual community that I can turn to.	20	24.2	12.4	31.6	31.8	2.71 (1.15)
When I feel lonely, I rely on people who share my spiritual or religious beliefs for support.	22	19.3	18.5	34.9	27.2	2.70 (1.07)
I seek out people in my religious or spiritual community when I need help.	23	33.2	32.2	21.5	13.0	2.14 (1.02)
Total						3.06 (0.78)

Note. Missing column represents the number of people with missing data on that item. Percentages of responses are based on the number of participants completing a given item. Response options range from 1 = *strongly disagree/none of the time* to 4 = *strongly agree/all of the time*.

Table 5

Parent Responses on Multidimensional Scale of Perceived Social Support Scale (MSPSS)

Subscale/Item	Missing	Percentage of responses							<i>M (SD)</i>
		1	2	3	4	5	6	7	
Family relationships									4.97 (1.55)
My family really tries to help me.	0	4.2	6.2	7.6	6.6	26.5	30.6	18.3	5.10 (1.62)
I can talk about my problems with my family.	1	5.7	6.3	8.3	7.2	25.2	28.4	18.9	5.01 (1.71)
My family is willing to help me make decisions.	0	5.9	6.0	7.9	10.4	21.0	30.2	18.5	4.99 (1.72)
I get the emotional help and support I need from my family.	0	5.5	7.9	11.9	7.8	26.1	25.5	15.3	4.79 (1.72)
Friend relationships									4.75 (1.58)
I have friends with whom I can share my joys and sorrows.	0	6.4	4.9	7.2	7.2	25.1	30.6	18.5	5.06 (1.70)
I can talk about my problems with my friends.	1	6.3	6.8	7.4	10.8	24.6	27.3	16.9	4.90 (1.72)
I can count on my friends when things go wrong.	1	8.1	7.8	10.4	14.8	24.1	22.2	12.7	4.56 (1.76)
My friends really try to help me.	1	7.8	7.4	12.1	17.0	24.4	20.6	10.6	4.47 (1.71)

Note. Missing column represents the number of people with missing data on that item. Percentages of responses are based on the number of participants completing a given item. Response options range from 1 = *very strongly disagree* to 7 = *very strongly agree*.

Table 6
Parent Responses on Family-Professional Partnership Scale Items

Subscale/Item	Missing	Percentage of responses					<i>M</i> (<i>SD</i>)
		Very Dissatisfied (1)	Dissatisfied (2)	Neither (3)	Satisfied (4)	Very Satisfied (5)	
<i>Your child's service provider...</i>							
Treats your son/daughter with dignity.	19	2.9	2.5	7.3	38.8	48.4	4.27 (0.92)
Keeps your son/daughter safe when your son/daughter is in his/her care.	23	1.6	2.8	12.3	40.5	42.9	4.20 (0.87)
Values your opinion about your son/daughter's needs.	21	5.3	5.9	12.2	37.4	39.2	3.99 (1.11)
Lets you know about the good things your son/daughter does.	18	6.5	5.9	13.9	38.0	35.8	3.91 (1.14)
Builds on your son/daughter's strengths.	22	3.7	8.1	16.2	40.8	31.2	3.88 (1.06)
Has the skills to help your son/daughter succeed.	17	6.1	6.4	15.0	43.4	29.1	3.83 (1.10)
Provides services that meet the individual needs of your son/daughter.	16	6.2	9.9	11.7	42.1	30.0	3.80 (1.16)
Speaks up for your son/daughter's best interests when working with other service providers.	19	6.5	7.8	19.6	36.3	29.8	3.75 (1.15)
Helps you gain skills or information to get what your son/daughter needs.	16	7.0	8.6	21.1	36.3	27.1	3.68 (1.16)
Uses words that you understand.	22	1.4	1.2	4.3	42.8	50.3	4.39 (0.75)
Is friendly.	22	2.0	2.4	6.1	40.8	48.7	4.32 (0.85)
Protects your family's privacy.	23	1.6	1.6	11.5	42.9	42.5	4.23 (0.83)
Shows respect for your family's values and beliefs.	21	2.2	2.6	11.4	40.4	43.5	4.20 (0.90)
Listens without judging your son/daughter or family.	21	2.4	3.5	12.6	42.7	38.8	4.12 (0.92)
Is honest, even when there is bad news to give.	21	2.6	3.3	13.4	44.5	36.2	4.08 (0.92)
Pays attention to what you have to say.	21	4.3	4.1	9.8	43.5	38.2	4.07 (1.02)
Is a person you can depend on and trust.	22	3.4	6.5	13.2	38.5	38.5	4.02 (1.04)
Is available when you need them.	18	5.3	7.4	14.7	43.1	29.5	3.84 (1.09)
Formal relationships							4.03 (0.86)

Note. Missing column represents the number of people with missing data on that item. Percentages of responses are based on the number of participants completing a given item.

Table 7
Bivariate Correlation Matrix for All Predictor and Outcome Variables

Variable	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18
1. FQOL Total	–																	
2. Child age	.04	–																
3. ASD [†]	-.26**	-.17**	–															
4. Disability severity	-.22**	.02	.21**	–														
5. Support needs	-.25**	-.12**	.25**	.54**	–													
6. Behaviors	.46**	.14**	-.43**	-.25**	-.29**	–												
7. Parent role (mother) [†]	.02	-.22**	.06	-.07	.02	.04	–											
8. Race/ethnicity (white only) [†]	.12**	.11**	-.06	.07	-.03	.04	.00	–										
9. Education	.12**	-.14**	.01	.03	.03	.02	-.02	.07	–									
10. Health status	.34**	-.08	-.10*	-.07	-.07	.20**	.04	.10*	.22**	–								
11. Household size	.04	-.42**	.11*	-.00	.09*	-.04	.10*	-.03	.10*	.06	–							
12. Household income	.23**	-.08	-.03	.02	-.01	.00	.02	.24**	.38**	.24**	.16**	–						
13. Public funding/support [†]	.03	.41**	.00	.03	-.02	-.01	-.06	.03	-.10*	-.08	-.32**	-.16**	–					
14. Overall religiousness/spirituality	.22**	.01	-.08	-.06	-.09*	.13**	.06	-.08	-.04	.05	.07	-.05	-.04	–				
15. Frequency of congregation attendance	.14**	-.02	-.06	-.02	-.11*	.10*	-.02	.05	.05	.10*	.11*	.00	-.08	.71**	–			
16. Family relationships	.68**	.14**	-.23**	-.16**	-.15**	.36**	-.01	.12**	.12**	.26**	.04	.19**	.05	.18**	.13**	–		
17. Friend relationships	.56**	.05	-.17**	-.18**	-.23**	.29**	.04	.08	.15**	.28**	-.04	.22**	.00	.22**	.16**	.64**	–	
18. Professional relationships	.49**	-.09*	-.02	-.13**	-.06	.18**	.08	.06	.08	.13**	.10*	.12**	-.03	.01**	.07	.35**	.33**	–

Note. $N = 529$. ASD = autism spectrum disorder. FQOL = Family Quality of Life. [†] Dichotomous variable.

* $p \leq .05$. ** $p \leq .01$.

Table 8

Regression Analyses Predicting Family Quality of Life Ratings

	Block 1		Block 2		Block 3	
	β	r	β	r	β	r
Child factors						
Behaviors	.35**	.30	.34**	.29	.18**	.15
Support needs	-.09*	-.07	-.08	-.07	-.09*	-.07
Child age	-.02	-.02	-.03	-.02	-.06	-.05
Autism spectrum disorder	-.06	-.05	-.05	-.04	-.04	-.04
Disability severity	-.07	-.06	-.07	-.06	-.01	-.00
Parent factors						
Health status	.21**	.20	.21**	.19	.12**	.10
Parent role (mother)	-.01	-.01	-.02	-.02	-.03	-.03
Race/ethnicity (white only)	.04	.04	.06	.06	.02	.02
Education	.00	.00	.02	.01	-.02	-.02
Family factors						
Household income	.17**	.15	.18**	.15	.09**	.07
Public funding/support	.10*	.09	.10*	.09	.06*	.05
Household size	.06	.05	.05	.04	.01	.01
Religious/spiritual factors						
Overall religiousness/spirituality			.23**	.16	.11**	.07
Frequency of congregation attendance			-.10	-.06	-.06	-.04
Relational factors						
Family relationships					.38**	.27
Professional relationships					.25**	.23
Friend relationships					.10**	.07
R^2	.334**		.364**		.630**	
Adjusted R^2	.319		.347		.617	
Change in R^2			.030**		.266**	

Note. $N = 529$. β = standardized beta coefficient. r = semipartial, or part, correlation.

* $p \leq .05$. ** $p < .01$.

Appendix A



Family Views on Quality of Life and Intellectual Disability

A Two-State Study: Illinois and Tennessee

This study is for parents with a son or daughter of any age with intellectual disability. We want to get to know a little about you, your family, and the kinds of things that help you experience the “good life.” This is sometimes called Family Quality of Life (FQOL) and this study is designed to help us learn about the things that help improve FQOL. The results of this study will be used to help people in all walks of life better understand how to support families like yours.

After a few preliminary questions about your son’s or daughter’s disability, we ask questions arranged in five sections about: (1) you and your family, (2) your son/daughter with intellectual disability, (3) aspects of your relationships with others, (4) aspects of your faith and religion/spirituality, and (5) aspects of parenting stress.

Altogether, this survey should take about 30 minutes to complete. Your responses to this questionnaire are entirely voluntary and anonymous. While complete answers to all questions are preferable, you should feel free to skip any questions that you wish. If you have more than one son/daughter with intellectual disability, please choose one and think only about that son/daughter as you answer the questions.

A check in the box below indicates that you have read and understand these conditions and that your responses may be used for research purposes.

All parents who submit a survey will be entered into a random drawing to receive one of 40 gift cards valued at \$25 each.

I have read and understand the terms of this agreement, and agree to take part in this study.

Yes No

PRESENCE OF INTELLECTUAL (AND OTHER) DISABILITY

1. Did a doctor, health professional, or special education professional ever tell you that [son/daughter's name] had an intellectual disability, previously referred to as mental retardation?
 Yes No
2. Did a doctor, health professional, or special education professional ever tell you that [son/daughter's name] had autism, Asperger's disorder, pervasive developmental disorder, or autism spectrum disorder?
 Yes No
3. Which of the following describes the disability or condition of your son or daughter? (*please check any that apply*)
 - Angelman syndrome
 - Cerebral Palsy
 - Cornelia de Lang syndrome
 - Down syndrome
 - Edward's syndrome
 - Fetal alcohol syndrome
 - Fragile X syndrome
 - Klinefelter syndrome
 - Lesch-Nyhan syndrome
 - Patau's syndrome
 - Prader-Willi syndrome
 - Rett syndrome
 - Smith-Magenis syndrome
 - Williams syndrome
 - 5p- (*cri du chat*) syndrome

I. INFORMATION ABOUT YOU AND YOUR FAMILY

1. How old are you? _____ years
2. What is your gender? Male Female
3. What is your relationship to the son/daughter with intellectual disability?
 - Mother
 - Father
 - Grandparent
 - Aunt/Uncle
 - Sibling
 - Other: _____ (please describe)
4. What best describes your marital status?
 - Married
 - Living as married
 - Separated or Divorced
 - Widowed
 - Single (not married and not living together)
5. What is your race/ethnicity? (check all that apply)
 - White (non-Hispanic)
 - African American/Black
 - Latina/Latino/Hispanic
 - American Indian or Alaska Native
 - Asian/Asian American
 - Other: _____ (please describe)

6. What is your highest level of education?
- Some high school
 - High school degree
 - Some college
 - 2 year degree
 - 4 year degree
 - Graduate/professional degree
 - None of the above. Please describe: _____
7. How many total children do you have (including son/daughter with intellectual disability)?

8. How many people (total—including you) currently live in your home (at least a majority of the time)? _____
9. In what state do you live?
- Illinois
 - Tennessee
 - Other (please describe): _____
10. Does your son/daughter with intellectual disability currently live with you (at least a majority of the time)?
- Yes
 - No
11. What is your Zip Code? _____
(This information will help us ensure we are capturing the views of parents across the state)
12. What best describes the community where you live? (check only one)
- Urban
 - Suburban
 - Rural
13. What best describes the amount of time you spend in paid employment?
- Full-time work
 - Part-time work
 - No paid employment
14. What is the overall annual income within your household?
- less than \$15,000
 - \$15,000-34,999
 - \$35,000-49,999
 - \$50,000-74,999
 - \$75,000-99,999
 - \$100,000 or more
15. How would you rate your health at the present time?
- Poor
 - Fair
 - Good
 - Very good
 - Excellent

16. Is your son or daughter with intellectual disability currently receiving any state or federally funded disability service benefits, funding, or services?

<input type="checkbox"/> Yes	<input type="checkbox"/> No
------------------------------	-----------------------------

17. *Family Quality of Life:* The following questions focus on your family and how you feel about your life together as a family. Your "family" may include many people—mother, father, partners, children, aunts, uncles, grandparents, etc. For this section, please consider your family as those people who:

- think of themselves as part of your family (even though they may or may not be related by blood or marriage), and
- support and care for each other **on a regular basis**.

For this section, please DO NOT think about relatives (extended family) who are only involved with your family every once in a while. Please think about your family life over the past 12 months.

The following items are things that hundreds of families have said are important for a good family quality of life. We want to know how satisfied you are with these things in your family. Please check the responses that reflect your level of satisfaction with each item.

How satisfied am I that...	Very dis-satisfied	Dis-satisfied	Neither	Satisfied	Very Satisfied
	1 ▼	2 ▼	3 ▼	4 ▼	5 ▼
My family enjoys spending time together.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My family members help the children learn to be independent.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My family has the support we need to relieve stress.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My family members have friends or others who provide support.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My family members help the children with schoolwork and activities.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My family members have transportation to get to the places they need to be.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My family members talk openly with each other.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My family members teach the children how to get along with others.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My family members have some time to pursue their own interests.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My family solves problems together.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My family members support each other to accomplish goals.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My family members show that they love and care for each other.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My family has outside help available to us to take care of special needs of all family members.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Adults in my family teach the children to make good decisions.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My family gets medical care when needed.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

How satisfied am I that...	Very dis-satisfied	Dis-satisfied	Neither	Satisfied	Very Satisfied
	1 ▼	2 ▼	3 ▼	4 ▼	5 ▼
My family has a way to take care of our expenses.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Adults in my family know other people in the children's lives (friends, teachers, etc.).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My family is able to handle life's ups and downs.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Adults in my family have time to take care of the individual needs of every child.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My family gets dental care when needed.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My family feels safe at home, work, school, and in our neighborhood.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My family member with a disability has support to accomplish goals at school or workplace.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My family member with a disability has support to accomplish goals at home.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My family member with a disability has support to make friends.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My family has good relationships with the service providers who provide services and support to our family member with a disability.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

18. For the previous Family Quality of Life questions, WHO did you include as part of your "family"? Please check ALL the types of people that apply.

At least one person who is...

- related to me biologically (blood relatives)
- related to me through marriage
- related to me through adoption
- my friend
- a member of my congregation
- my neighbor
- my co-worker
- other (please explain): _____

II. INFORMATION ABOUT YOUR SON/DAUGHTER WITH INTELLECTUAL DISABILITY

1. How old is your son/daughter with an intellectual disability? _____ years
2. What is his or her gender? Male Female
3. *School Status:* Which best describes your son/daughter's school status? My son or daughter is...
 - not yet old enough for school
 - in pre-school or kindergarten
 - in elementary or middle school
 - in high school
 - in a post-secondary education program

- out of school
- other (please explain): _____

4. *Educational Setting:* In what setting does, did, or will your son or daughter receive the majority of their K-12 education?

- public school
- private school
- home school
- other (please explain): _____

5. *Disability Severity:* How would you describe your son/daughter’s level of disability?

- Mild
- Moderate
- Severe
- Very Severe

6. *Support Needs:* The following items will help us understand how much support your son/daughter typically needs for different activities in different settings. Read the name and description of each support area below and check the amount of support your son/daughter needs on a scale of 1 (no extra support) to 5 (total support). **Make your ratings in relation to other people without disabilities of the same age.** Provide your best estimate.

How Much Support Does Your Son/Daughter Typically Need?	Overall support needs. Check one.				
	No extra support	A little support	Medium support	Much support	Total support
	1 ▼	2 ▼	3 ▼	4 ▼	5 ▼
Home Living Activities Activities such as completing household chores, eating, washing and keeping self clean, dressing, using the toilet, sleeping and/or napping, keeping track of personal belongings, keeping occupied during free time, or operating electronic devices.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Community and Neighborhood Activities Activities such as moving around the community or neighborhood, participating in leisure activities, using public services, participating in community service and religious activities, shopping, complying with community standards/rules/laws, or attending special events like cookouts/picnics, cultural festivals, holiday events, etc...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Social Activities Activities such as maintaining positive relations with others, respecting the rights of others, maintaining conversation, responding to/providing constructive criticism, coping with changes in routines or transitions across social situations, making and keeping friends, or protecting self from exploitation and bullying, communicating with others in social situations, respecting others personal space/property.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

How Much Support Does Your Son/Daughter Typically Need?	Overall support needs. <i>Check one.</i>				
	No extra support	A little support	Medium support	Much support	Total support
	1 ▼	2 ▼	3 ▼	4 ▼	5 ▼
<p>Health and Safety Activities</p> <p>Activities such as communicating health-related issues and medical problems, maintaining physical fitness, emotional well-being, or health, implementing routine first aid, responding in emergency situations, protecting self against abuse, or avoiding safety and health hazards.</p>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<p>Advocacy Activities</p> <p>Activities such as expressing personal preferences, setting personal goals, taking action and attaining goals, making choices and decisions, advocating for and assisting others, learning and using self-advocacy skills, communicating personal wants and needs, participating in educational decision making, or learning problem solving strategies.</p>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<p>Learning Activities <i>(use the set of items corresponding to your son/daughter's age)</i></p> <p><i>(refer to these if your son/daughter is school age or younger)</i> School Learning: Activities such as accessing grade level curriculum content, learning academic skills or tasks, using learning strategies or problem solving strategies, participating in tests, accessing health and PE curricula, or completing homework assignments.</p> <p><i>(refer to these if your son/daughter is older than school age)</i> Lifelong Learning: Accessing training/educational settings, learning and using problem solving strategies, using technology for learning, learning health and physical education skills, learning self-management skills, learning self-determination skills, learning functional academics (reading signs, counting change, etc.), interacting with others in learning activities, participating in training/educational decisions</p>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<p>School or Work Participation Activities <i>(use the set of items corresponding to your son/daughter's age)</i></p> <p><i>(refer to these if your son/daughter is school age or younger)</i> School Participation: Activities such as being included in general education classrooms, participating in non-classroom school activities, participating in co-curricular activities, getting to school, moving around the school, following classroom and school rules, keeping track of a schedule, or keeping track of personal belongings at school.</p> <p><i>(refer to these if your son/daughter is older than school age)</i> Work Participation: Learning and using specific job skills, interacting with co-workers, interacting with supervisors/coaches, completing work-related tasks with acceptable speed, completing work-related tasks with acceptable quality, changing job assignments, seeking information and assistance from an employer, accessing/receiving job/task accommodations.</p>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

7. *Challenging Behaviors:* The following questions relate to the presence, frequency, and seriousness of eight types of potentially challenging behaviors your son/daughter with intellectual disability may exhibit. Consider your son/daughter's behavior over the past 6 months.

<p>In the past 6 months (including now), has your son/daughter experienced any of the following eight behaviors? <i>If so, please indicate how OFTEN they occur and how SERIOUS a problem you consider it to be.*</i></p>	<p><i>*Only answer the 2 following questions after each behavior about how OFTEN and SERIOUS if you answered "Yes" about the behavior occurring. If you answer No, the behavior is not occurring, leave the 2 following questions blank.</i></p>				
A) Has your son/daughter been hurtful to him/herself; injured own body by hitting, banging head, or scratching?	<input type="checkbox"/> Yes		<input type="checkbox"/> No		
How OFTEN does this occur?	<input type="checkbox"/> Less than once a month	<input type="checkbox"/> 1-3 times per month	<input type="checkbox"/> 1-6 times per week	<input type="checkbox"/> 1-10 times a day	<input type="checkbox"/> 1 or more times an hour
How SERIOUS is this behavior?	<input type="checkbox"/> Not	<input type="checkbox"/> Slightly	<input type="checkbox"/> Moderately	<input type="checkbox"/> Very	<input type="checkbox"/> Extremely
B) Has your son/daughter been destructive or hurtful to others; caused physical pain to other people or to animals?	<input type="checkbox"/> Yes		<input type="checkbox"/> No		
How OFTEN does this occur?	<input type="checkbox"/> Less than once a month	<input type="checkbox"/> 1-3 times per month	<input type="checkbox"/> 1-6 times per week	<input type="checkbox"/> 1-10 times a day	<input type="checkbox"/> 1 or more times an hour
How SERIOUS is this behavior?	<input type="checkbox"/> Not	<input type="checkbox"/> Slightly	<input type="checkbox"/> Moderately	<input type="checkbox"/> Very	<input type="checkbox"/> Extremely
C) Has your son/daughter been destructive to property; deliberately defaced or destroyed things?	<input type="checkbox"/> Yes		<input type="checkbox"/> No		
How OFTEN does this occur?	<input type="checkbox"/> Less than once a month	<input type="checkbox"/> 1-3 times per month	<input type="checkbox"/> 1-6 times per week	<input type="checkbox"/> 1-10 times a day	<input type="checkbox"/> 1 or more times an hour
How SERIOUS is this behavior?	<input type="checkbox"/> Not	<input type="checkbox"/> Slightly	<input type="checkbox"/> Moderately	<input type="checkbox"/> Very	<input type="checkbox"/> Extremely
D) Has your son/daughter had disruptive behavior; interfered with the activity of others by clinging, pestering, or teasing?	<input type="checkbox"/> Yes		<input type="checkbox"/> No		
How OFTEN does this occur?	<input type="checkbox"/> Less than once a month	<input type="checkbox"/> 1-3 times per month	<input type="checkbox"/> 1-6 times per week	<input type="checkbox"/> 1-10 times a day	<input type="checkbox"/> 1 or more times an hour
How SERIOUS is this behavior?	<input type="checkbox"/> Not	<input type="checkbox"/> Slightly	<input type="checkbox"/> Moderately	<input type="checkbox"/> Very	<input type="checkbox"/> Extremely
E) Has your son/daughter had any unusual or repetitive habits; unusual behavior done over and over like pacing, rocking, twirling fingers, or talking to him/herself?	<input type="checkbox"/> Yes		<input type="checkbox"/> No		
How OFTEN does this occur?	<input type="checkbox"/> Less than once a month	<input type="checkbox"/> 1-3 times per month	<input type="checkbox"/> 1-6 times per week	<input type="checkbox"/> 1-10 times a day	<input type="checkbox"/> 1 or more times an hour
How SERIOUS is this behavior?	<input type="checkbox"/> Not	<input type="checkbox"/> Slightly	<input type="checkbox"/> Moderately	<input type="checkbox"/> Very	<input type="checkbox"/> Extremely

<p>In the past 6 months (including now), has your son/daughter experienced any of the following eight behaviors? <i>If so, please indicate how OFTEN they occur and how SERIOUS a problem you consider it to be.*</i></p>	<p><i>*Only answer the 2 following questions after each behavior about how OFTEN and SERIOUS if you answered "Yes" about the behavior occurring. If you answer No, the behavior is not occurring, leave the 2 following questions blank.</i></p>				
F) Has your son/daughter had withdrawn or inattentive behavior; difficulty being around others or paying attention?	<input type="checkbox"/> Yes		<input type="checkbox"/> No		
How OFTEN does this occur?	<input type="checkbox"/> Less than once a month	<input type="checkbox"/> 1-3 times per month	<input type="checkbox"/> 1-6 times per week	<input type="checkbox"/> 1-10 times a day	<input type="checkbox"/> 1 or more times an hour
How SERIOUS is this behavior?	<input type="checkbox"/> Not	<input type="checkbox"/> Slightly	<input type="checkbox"/> Moderately	<input type="checkbox"/> Very	<input type="checkbox"/> Extremely
G) Has your son/daughter had any socially offensive behavior; such as talking too loudly, swearing, touching others too much, or belching?	<input type="checkbox"/> Yes		<input type="checkbox"/> No		
How OFTEN does this occur?	<input type="checkbox"/> Less than once a month	<input type="checkbox"/> 1-3 times per month	<input type="checkbox"/> 1-6 times per week	<input type="checkbox"/> 1-10 times a day	<input type="checkbox"/> 1 or more times an hour
How SERIOUS is this behavior?	<input type="checkbox"/> Not	<input type="checkbox"/> Slightly	<input type="checkbox"/> Moderately	<input type="checkbox"/> Very	<input type="checkbox"/> Extremely
H) Has your son/daughter had uncooperative behavior; refusing to obey or refusing to go to school or work?	<input type="checkbox"/> Yes		<input type="checkbox"/> No		
How OFTEN does this occur?	<input type="checkbox"/> Less than once a month	<input type="checkbox"/> 1-3 times per month	<input type="checkbox"/> 1-6 times per week	<input type="checkbox"/> 1-10 times a day	<input type="checkbox"/> 1 or more times an hour
How SERIOUS is this behavior?	<input type="checkbox"/> Not	<input type="checkbox"/> Slightly	<input type="checkbox"/> Moderately	<input type="checkbox"/> Very	<input type="checkbox"/> Extremely

III. INFORMATION ABOUT YOUR RELATIONSHIPS WITH OTHERS

1. We are interested in how you feel about the following statements. Read each statement carefully and indicate and rate your level of agreement.

How much do I agree that...	Very strongly disagree	Strongly disagree	Mildly disagree	Neutral	Mildly agree	Strongly agree	Very strongly agree
	1 ▼	2 ▼	3 ▼	4 ▼	5 ▼	6 ▼	7 ▼
My family really tries to help me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I get the emotional help & support I need from my family.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My friends really try to help me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

How much do I agree that...	Very strongly disagree	Strongly disagree	Mildly disagree	Neutral	Mildly agree	Strongly agree	Very strongly agree
	1 ▼	2 ▼	3 ▼	4 ▼	5 ▼	6 ▼	7 ▼
I can count on my friends when things go wrong.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I can talk about my problems with my family.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I have friends with whom I can share my joys and sorrows.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My family is willing to help me make decisions.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I can talk about my problems with my friends.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
For the next 4 questions, consider the disability-related service providers in your life such as special education teachers, physical or speech therapists, doctors, case managers or others.							
The disability-related service providers in my life provide me with emotional support.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The disability-related service providers in my life really try to help me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I can talk about my problems with the disability-related service providers in my life.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The disability-related service providers in my life are there for me when I need them.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

2. *Family-Professional Partnership:* The following questions are about how you feel about the main person who works with you and your son/daughter with intellectual disability. There may be many service providers you work with such as teachers, social workers, or therapists. Think about the service provider who has worked **THE MOST** with your son/daughter over the **last six months**. Please tell us what type of provider you are thinking about:

- Education service provider
- Health care provider
- Related services provider (including intervener)
- Child care provider
- Service coordinator
- Other: (please specify) _____

How satisfied are you that this service provider...	Very dis-satisfied	Dis-satisfied	Neither	Satisfied	Very Satisfied
	1 ▼	2 ▼	3 ▼	4 ▼	5 ▼
Helps you gain skills or information to get what your son/daughter needs.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Has the skills to help your son/daughter succeed.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Provides services that meet the individual needs of your son/daughter.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Speaks up for your son/daughter's best interests when working with	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

How satisfied are you that this service provider...	Very dis-satisfied	Dis-satisfied	Neither	Satisfied	Very Satisfied
	1 ▼	2 ▼	3 ▼	4 ▼	5 ▼
other service providers.					
Lets you know about the good things your son/daughter does.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Is available when you need them.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Treats your son/daughter with dignity.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Builds on your son/daughter's strengths.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Values your opinion about your son/daughter's needs.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Is honest, even when there is bad news to give.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Keeps your son/daughter safe when your son/daughter is in his/her care.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Uses words that you understand.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Protects your family's privacy.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Shows respect for your family's values and beliefs.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Listens without judging your son/daughter or family.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Is a person you can depend on and trust.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Pays attention to what you have to say.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Is friendly.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

3. *Number of Relationships*: Consider the types of people with whom you have relationships. Answer each of the following questions by describing the number of people that fit each relationship category below: *Friend, Family, Disability-related professional, and Other*.

What best characterizes the <u>number</u> of the following types of relationships you have?	Don't really have any ▼	One or two ▼	Three to Five ▼	Six to Ten ▼	More than Ten ▼
My relationships with friends.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My relationships with family members.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My relationships with people who provide disability-related supports and services.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other types of relationships I have with people outside my family but aren't really friends or disability-related professionals.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Please describe what TYPES of people you included in the previous question who are outside of your family system but you don't really consider friends or disability-related professionals: _____					

IV. INFORMATION ABOUT ASPECTS OF FAITH & RELIGION/SPIRITUALITY

1. The following questions address various aspects of your religion/spirituality.

Answer each question using the four response options.	1 ▼	2 ▼	3 ▼	4 ▼
Religion is important in my day-to-day life.	<input type="checkbox"/> Strongly Disagree	<input type="checkbox"/> Somewhat Disagree	<input type="checkbox"/> Somewhat Agree	<input type="checkbox"/> Strongly Agree
Prayer or meditation has helped me cope during times of serious stress.	<input type="checkbox"/> None of the time	<input type="checkbox"/> A little bit of the time	<input type="checkbox"/> A good bit of the time	<input type="checkbox"/> All of the time
I enjoy attending religious functions held by my religious or spiritual group.	<input type="checkbox"/> Strongly Disagree	<input type="checkbox"/> Somewhat Disagree	<input type="checkbox"/> Somewhat Agree	<input type="checkbox"/> Strongly Agree
I feel certain that God in some form exists.	<input type="checkbox"/> Strongly Disagree	<input type="checkbox"/> Somewhat Disagree	<input type="checkbox"/> Somewhat Agree	<input type="checkbox"/> Strongly Agree
When I need suggestions on how to deal with problems, I know someone in my religious or spiritual community that I can turn to.	<input type="checkbox"/> Strongly Disagree	<input type="checkbox"/> Somewhat Disagree	<input type="checkbox"/> Somewhat Agree	<input type="checkbox"/> Strongly Agree
I believe God will not give me a burden I cannot carry.	<input type="checkbox"/> Strongly Disagree	<input type="checkbox"/> Somewhat Disagree	<input type="checkbox"/> Somewhat Agree	<input type="checkbox"/> Strongly Agree
I enjoy meeting or talking often with people who share my religious or spiritual beliefs.	<input type="checkbox"/> None of the time	<input type="checkbox"/> A little bit of the time	<input type="checkbox"/> A good bit of the time	<input type="checkbox"/> All of the time
During times of stress, my religious or spiritual beliefs have been strengthened.	<input type="checkbox"/> Strongly Disagree	<input type="checkbox"/> Somewhat Disagree	<input type="checkbox"/> Somewhat Agree	<input type="checkbox"/> Strongly Agree
When I feel lonely, I rely on people who share my spiritual or religious beliefs for support.	<input type="checkbox"/> Strongly Disagree	<input type="checkbox"/> Somewhat Disagree	<input type="checkbox"/> Somewhat Agree	<input type="checkbox"/> Strongly Agree
I have experienced a sense of hope as a result of my religious or spiritual beliefs.	<input type="checkbox"/> Strongly Disagree	<input type="checkbox"/> Somewhat Disagree	<input type="checkbox"/> Somewhat Agree	<input type="checkbox"/> Strongly Agree
I have experienced peace of mind through my prayers and meditation.	<input type="checkbox"/> Strongly Disagree	<input type="checkbox"/> Somewhat Disagree	<input type="checkbox"/> Somewhat Agree	<input type="checkbox"/> Strongly Agree
One's life and death follows a plan from God.	<input type="checkbox"/> Strongly Disagree	<input type="checkbox"/> Somewhat Disagree	<input type="checkbox"/> Somewhat Agree	<input type="checkbox"/> Strongly Agree
I seek out people in my religious or spiritual community when I need help.	<input type="checkbox"/> None of the time	<input type="checkbox"/> A little bit of the time	<input type="checkbox"/> A good bit of the time	<input type="checkbox"/> All of the time
I believe God protects me from harm.	<input type="checkbox"/> Strongly Disagree	<input type="checkbox"/> Somewhat Disagree	<input type="checkbox"/> Somewhat Agree	<input type="checkbox"/> Strongly Agree
I pray for help during bad times.	<input type="checkbox"/> None of the time	<input type="checkbox"/> A little bit of the time	<input type="checkbox"/> A good bit of the time	<input type="checkbox"/> All of the time

2. Please answer the following questions about your own religious faith using the scale below. Check the box to indicate your level of agreement or disagreement for each statement.

To what extent do you agree or disagree with each statement?	Strongly disagree ▼	Disagree ▼	Agree ▼	Strongly agree ▼
I pray daily.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I look to my faith as providing meaning and purpose in my life.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I consider myself to be active in my faith or congregation.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I enjoy being around others who share my faith.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My faith impacts many of my decisions.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

3. With what religious tradition do you most closely identify? *Check all that apply.*

- | | |
|---|--|
| <input type="checkbox"/> I don't identify with a particular religion. | <input type="checkbox"/> Episcopal |
| <input type="checkbox"/> Adventist | <input type="checkbox"/> Hindu |
| <input type="checkbox"/> African Methodist | <input type="checkbox"/> Holiness |
| <input type="checkbox"/> Anabaptist | <input type="checkbox"/> Jehovah's Witnesses |
| <input type="checkbox"/> Anglican | <input type="checkbox"/> Jewish |
| <input type="checkbox"/> Assemblies of God | <input type="checkbox"/> Latter-day Saints |
| <input type="checkbox"/> Baha'i | <input type="checkbox"/> Lutheran |
| <input type="checkbox"/> Baptist | <input type="checkbox"/> Mennonite |
| <input type="checkbox"/> Bible Church | <input type="checkbox"/> Methodist |
| <input type="checkbox"/> Brethren | <input type="checkbox"/> Muslim |
| <input type="checkbox"/> Buddhist | <input type="checkbox"/> Orthodox (i.e. Eastern, Oriental) |
| <input type="checkbox"/> Catholic/Roman Catholic | <input type="checkbox"/> Pentecostal |
| <input type="checkbox"/> Chinese Folk Religion | <input type="checkbox"/> Presbyterian |
| <input type="checkbox"/> Christian & Missionary Alliance | <input type="checkbox"/> Quaker/Friends |
| <input type="checkbox"/> Christian Reformed | <input type="checkbox"/> Reformed Church of America/Dutch Reformed |
| <input type="checkbox"/> Christian Science | <input type="checkbox"/> Salvation Army |
| <input type="checkbox"/> Church of Christ | <input type="checkbox"/> Seventh-day Adventist |
| <input type="checkbox"/> Church of God | <input type="checkbox"/> Unitarian Universalist |
| <input type="checkbox"/> Church of the Nazarene | <input type="checkbox"/> United Church of Christ |
| <input type="checkbox"/> Congregational | <input type="checkbox"/> Non-denominational Christian |
| <input type="checkbox"/> Disciples of Christ | <input type="checkbox"/> Other (please specify): _____ |
| | <input type="checkbox"/> I don't know |

4. How often do you attend religious services? *Select only one.*

<input type="checkbox"/> Never <input type="checkbox"/> Less than once a year <input type="checkbox"/> Once or twice a year <input type="checkbox"/> Several times a year <input type="checkbox"/> Once a month	<input type="checkbox"/> 2-3 times a month <input type="checkbox"/> About weekly <input type="checkbox"/> Weekly <input type="checkbox"/> Several times a week
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5. Below is a list of different spiritual or religious activities in which some people might participate in or through a congregation. Indicate whether, and to what extent, you participate in each activity.

Activities In or Through a Congregation	About how often do you participate in each activity?				
	Seldom /never ▼	Several times a year ▼	Once or twice a month ▼	At least once a week ▼	Don't know ▼
Serving as an usher or greeter	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Serving as an acolyte or alter server	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Serving in the choir or on a music team	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Leading scripture readings during religious services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Leading prayers publically during religious services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Attending a Sunday school or religious education class	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Participating in a prayer, study, or small group	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Participating in prayer meetings	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Attending a religious retreat, conference, rally, or congress	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Participating in sacraments (e.g., communion, confession, anointing)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Participating in local outreach activities (e.g., serving a community center, visiting shut-ins)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Participating in a national or international mission activities (e.g., short-term trips)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Performing other forms of service for the congregation (write in): _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Attending congregational fellowships, potlucks, and other social gatherings	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Participating in other congregational activities (write in): _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

6. How long have you attended your current place of worship (congregation/faith community)?
_____ years
7. How important is spirituality in your day-to-day life?
- Very important
 - Somewhat important
 - A little important
 - Not important

IV. Possible Sources of Parenting Stress

The following questions relate to various sources of stress for many parents. Read each statement carefully. For each statement, please focus on the son/daughter with intellectual disability and select the response that best represents your opinion. **Answer all questions about the same son/daughter.** While you may not find a response that exactly states your feelings, please select the response that comes closest to describing how you feel. **Your first reaction to each question should be your answer.**

***Please pay close attention to the labels of the options below and select the best response.**

How much do you agree with each of the following statements?	Strongly agree	Agree	Not sure	Disagree	Strongly disagree
<i>*Please note in the items below, the term "child" refers to your son or daughter of any age with intellectual disability.</i>	1 ▼	2 ▼	3 ▼	4 ▼	5 ▼
I often have the feeling that I cannot handle things very well.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I find myself giving up more of my life to meet my child's needs than I ever expected.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I feel trapped by my responsibilities as a parent.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Since having my child I have been unable to try new and different things.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Since having my child I feel that I am almost never able to do things that I like to do.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am unhappy with the last purchase of clothing I made for myself.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
There are quite a few things that bother me about my life.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Having a child has caused more problems than I expected in my relationship with my spouse.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I feel alone and without friends.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
When I go to a party I usually expect not to enjoy myself.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am not as interested in people as I used to be.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I don't enjoy things as I used to.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My child rarely does things for me that make me feel good.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
When I do things for my child, I get the feeling that my efforts are not appreciated very much.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My child smiles at me much less than I expected.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sometimes I feel my child doesn't like me and doesn't want to be close to me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My child is very emotional and gets upset easily.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My child doesn't seem to learn as quickly as most children.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My child doesn't seem to smile as much as most children.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My child is not able to do as much as I expected.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
It takes a long time and it is very hard for my child to get used to new things.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I feel that I am: (Choose a response from the choices below.) 1. a very good parent. 2. a better-than-average parent. 3. an average parent. 4. a person who has some trouble being a parent. 5. not very good at being a parent.	1	2	3	4	5
I expected to have closer and warmer feelings for my child than I do, and this bothers me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

How much do you agree with each of the following statements?	Strongly agree	Agree	Not sure	Disagree	Strongly disagree
<i>*Please note in the items below, the term "child" refers to your son or daughter of any age with intellectual disability.</i>	1 ▼	2 ▼	3 ▼	4 ▼	5 ▼
Sometimes my child does things that bother me just to be mean.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My child seems to cry or fuss more often than most children.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My child generally wakes up in a bad mood.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I feel that my child is very moody and easily upset.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Compared to the average child, my child has a great deal of difficulty in getting used to change in schedules or changes around the house.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My child reacts very strongly when something happens that my child doesn't like.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
When playing, my child doesn't often giggle or laugh.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My child's sleeping or eating schedule was much harder to establish than I expected.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I have found that getting my child to do something or stop doing something is: (Choose a response from the choices below.) 1. much harder than I expected. 2. somewhat harder than I expected. 3. about as hard as I expected. 4. somewhat easier than I expected. 5. much easier than I expected.	1	2	3	4	5
Think carefully and count the number of things which your child does that bother you. For example, dawdles, refuses to listen, overactive, cries, interrupts, fights, whines, etc. (Choose a response form the choices below.) 1. 1-3 2. 4-5 3. 6-7 4. 8-9 5. 10+	1	2	3	4	5
There are some things my child does that really bother me a lot.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My child's behavior is more of a problem than I expected.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My child makes more demands on me than most children.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

*** Thank you for participating in our Family Quality of Life study! ***

(Don't forget to fill out the information on the included page so we can enter your name into the gift card drawing!)

